



THE UNIVERSITY *of* EDINBURGH

This thesis has been submitted in fulfilment of the requirements for a postgraduate degree (e.g. PhD, MPhil, DClinPsychol) at the University of Edinburgh. Please note the following terms and conditions of use:

This work is protected by copyright and other intellectual property rights, which are retained by the thesis author, unless otherwise stated.

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge.

This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the author.

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author.

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given.

Understanding the supportive care needs of glioma patients
and their relatives: a qualitative longitudinal study

Debbie Cavers



PhD

The University of Edinburgh

2010



Submission of PhD
Declaration of authorship

I declare that the thesis is the result of my own work and has not, whether in the same or a different form, been presented to this or any other university in support of an application for any other degree than that for which I am now a candidate.

Signed

Printed name

Date

Acknowledgements

I would like to primarily thank my supervisors Professor Scott Murray, Dr. Belinda Hacking and Dr. Sara Erridge for all of their help, support and advice (including commenting on drafts) in producing this thesis and Mrs. Eilidh Wiseman for her financial support in making this project possible. I gained additional support and advice from Dr. Marilyn Kendall, Dr. Paul Morris and Ms. Shanne McNamara. Professor Ian Whittle and Dr. Robin Grant also provided support and access to their patients. Thank you also to all of the nurse practitioners and junior doctors who helped me with recruitment. Jen, Julie, Claire, Jackie and other friends in the ECNO office provided me with a happy and supportive working environment. Anna Lloyd, Emma Carduff and other members of the GPPhD Peer Group were on hand to listen and provide excellent advice on how to handle the PhD process and proof reading chapters. Likewise the members of the Primary Palliative Care Research Group gave expertise and support in conducting my research study.

I would like to thank my Mum and Dad for their continued love and support in everything I have endeavoured to do. All of my friends and family have given me the support network I needed to balance work and social life, priorities that have been emphasised through the learning process of my study. I would like to send a world of thanks and gratitude to my husband Graeme and son Finn who have been my inspiration and motivation to do my very best.

I would like to dedicate this thesis to all of the people who took part in this study: to those who continue to battle with their brain tumour and for those who have sadly lost their lives; and their relatives who struggle on with the effects of the disease. Thank you for sharing your most personal experiences with me.

This project is in memory of John Wiseman whose legacy inspired this study.

Abstract

Background: Malignant cerebral glioma is a rare cancer but has a devastating impact on patients and their families. In Scotland each year, around 450 people are diagnosed with glioma. Prognosis is generally poor and treatment is essentially palliative. There is a growing recognition that non-clinical aspects of care for both patients and their families need to be acknowledged and integrated into health care provision in line with a patient-focused ethos of care. Currently, there is relatively little research exploring the psychosocial issues and needs of this patient group.

Aims: To give patients being investigated for malignant cerebral glioma and their families the opportunity to describe their shared experiences of their illness journey and voice their concerns and unmet needs. To examine how these experiences and needs change over time as the patient progresses through the illness journey. To ascertain the extent to which these needs are recognised and supported, taking into accounts professionals' views and making suggestions for steps forward in improving patients' psychosocial care.

Methods: A total of 80 qualitative prospective longitudinal interviews (30 paired and 50 separate) were conducted with 26 people with a suspected or confirmed diagnosis of malignant cerebral glioma being treated at a regional hospital and 24 primary relative/informal carers. Patients and carers were interviewed at the following five times: leading up to diagnosis; following a formal diagnosis; around the end of initial treatment (radiotherapy); at a designated six-month follow-up stage; and bereavement interviews with carers. One-off interviews were carried out with 66 health professionals (19 case-linked GPs and 47 other health, health-related and social care professionals involved in patients' care). Interviews were recorded and transcribed verbatim and analysed using the constant comparative method from a grounded theory approach assisted by QSR NVivo Version 7.

Findings: Distress, anxiety and shock were overwhelming reactions in the period leading up to a diagnosis of glioma, making it difficult for participants to make sense of their experience. Over time, participants employed a range of strategies in order to cope with their diagnosis. Social and emotional support from professionals and friends, family and other patients were vital in many cases but support often felt inadequate. The role of information and the manner in which it was communicated was closely linked to participants' ability to cope. Information needs were variable but on the whole patients and carers did not feel well informed. Dealing with cognitive and physical symptoms of their illness and side effects of treatment inhibited patients' ability to resume their everyday activities. The lives of relatives were also affected as they struggled to care for their loved ones. People with a diagnosis of glioma were faced with the possibility of death from an early point in their illness trajectory and awareness of this, coupled with ability to make sense of existential issues, varied across participants. Issues around support, communication, information and palliative care were considered to be important among health professionals involved in the care of people with a diagnosis of glioma but provision fell short.

Conclusions: Concerns regarding information, communication and support reported elsewhere in the literature are enduring in glioma patients and their relatives. Reporting of unmet psychosocial and supportive care issues by patients and recognition by professionals of the need to improve these dimensions of care for people affected by glioma emphasises previous recommendations yet to be fully implemented into patient care.

Prologue and overview of thesis

This study has been inspired and funded by the widow of a man with a malignant glioma to explore the different dimensions of living with the disease. She felt that the neuro-oncology service was lacking in terms of information and psychosocial support offered to patients and their families and so made funding available so that recommendations could be made to improve people's experiences of this service. This combined with my own personal interest in human agency, oncology, palliative care and qualitative research led to the development of this study. This research study has occurred within the medical school of a university but is based on a psychological and social science approach to understanding the experience of living with a glioma.

Coming from a background in psychology, I have long had a curiosity about the human condition which has evolved into a keen interest in human lives and experiences of illness. I chose a qualitative longitudinal approach so that I could explore and understand the dynamic lived experiences of people with a glioma diagnosis and their carers. The outline of the thesis is as follows:

Chapter one provides an introduction to malignant cerebral glioma and how it may affect patients and families' lives. An overview of current service provision and current attempts to improve patient care are presented. The rationale for further in-depth qualitative research to better understand the lived experience of the disease is identified, with particular emphasis on capturing the process of diagnosis and the dynamics of the experience as the illness progresses.

Chapter two is a review of background literature pertaining to issues for glioma patients in particular as well as more general issues for people suffering with other life-threatening cancers and in need of information and supportive and palliative care.

Chapter three examines the methodological considerations and ethical challenges of conducting research with people with progressive life-limiting illness. It also details the chosen design and methods of the study, with justification for choosing this approach.

Chapter four reports on the participants and interviews actually conducted. The timing and other details of the longitudinal interviews conducted are summarised in this chapter. This allows an overview of the stages of the study that evolved, and should make the findings reported in the following six chapters easier to interpret.

The findings from this study have been structured into chapters reflecting the main themes to emerge from the data which did not always relate to specific time points in the illness journey. Many of the issues endured in different forms throughout and varied for each individual. Chapters five to nine focus on patient and carer views, and chapter 10 presents the views of health professionals.

Chapter five highlights a key transition phase marking the beginning of a person's illness journey before a diagnosis is confirmed, a stage that has been given little previous attention. How people dealt with complex symptoms and emotions, and the pathway to reaching a diagnosis are explored.

Chapter six reports on the emotional response and process of adjustment to a devastating diagnosis, detailing the coping strategies used by patients and their relatives. The roles of hope and support are reported. Key concerns for family carers are also presented.

Chapter seven details issues surrounding the presence or lack of information and communication that evolved over time. The significant role of information and communication in supporting people and aiding adjustment are highlighted.

Chapter eight describes the 'biographical disruption' of living with a glioma and the impact on the multiple dimensions of people's lives in addition to steps taken to adapt and rebuild their lives.

Chapter nine explores the issues of death and dying people faced. Access and attitudes to palliative care services are reported in addition to the existential quest undertaken by some patients and relatives in their attempt to make sense of their experiences. The experiences of bereaved relatives are also presented.

Chapter ten presents an overview of services and key areas for improvement of psychosocial care reported from the perspective of professionals in contact with people with a glioma diagnosis.

Chapter eleven, the discussion, reflects on the methods used and the findings from the previous six chapters and discusses how these resonate with current thinking on understanding illness experience. The strengths and weaknesses of the approach and methods used are also discussed.

Chapter twelve offers conclusions on the research findings, suggests further research that is indicated and presents recommendations to improve patient care.

Table of contents

Acknowledgements.....	2
Abstract	3
Prologue and overview of thesis	5
Table of contents	8
Chapter One: Introduction, rationale and aims	15
1.1 Malignant cerebral glioma	15
1.2 Management of glioma patients.....	20
1.3 Improving treatment and care for glioma patients	21
1.3.1 Best practice in the management of gliomas	22
1.3.2 Psychosocial and supportive care	23
1.3.3 Palliative care services	25
1.3.4 Specialist nurse support	27
1.3.5 Other sources of support for glioma patients	28
1.4 Understanding the illness experience	29
1.4.1 Moving towards patient-centred care	29
1.4.2 Telling your illness story	31
1.5 Setting the research agenda	31
1.6 Aims and objectives	32
Summary of aims:.....	32
Chapter Two: Review of the literature exploring the experience of a malignant brain tumour	34
Introduction.....	34
2.1 Living with glioma – defining the review agenda	34
2.2 The literature	35
2.3 Review methodology	35
2.4 Findings	36
2.4.1 Reaching a diagnosis.....	37
2.4.2 Living with a brain tumour	38
2.4.3 Psychological issues.....	43
2.4.3.1 Distress	43
2.4.3.2 Coping.....	46
2.4.3.3 Hope	50
2.4.3.4 Clinical depression/ anxiety	53
2.4.4 Information and communication	53
2.4.4.1 Information and communication for brain tumour patients.....	53
2.4.4.2 Information and communication for patients with a general cancer diagnosis.....	55
2.4.4.3 Breaking bad news	59
2.4.4.4 Information and communication at the end of life.....	61
2.4.4.5 Improving information and communication in oncology.....	63
2.4.5 Supportive care needs	64
2.4.5.1 Supportive care in neuro-oncology	65
2.4.5.2 Supportive care for all cancer patients and carers	67
2.4.6 Social network and support.....	71

2.4.6.1 Supportive relationships	71
2.4.6.2 Support groups	72
2.4.6 Quality of life	72
2.4.7 Carers	77
2.4.7 Spirituality/ existential issues	80
2.4.8 Palliative care provision	83
2.5 Summary	85
Chapter Three: Methodology	86
3.1 Introduction	86
3.2 A qualitative approach	86
3.2.1 Ontology, Epistemology and theoretical perspectives	87
3.2.2 Carving out a position	89
3.2.3 Methodology	90
3.2.4 Qualitative interviews	93
3.2.4.1 Timing and content of interviews	95
3.2.4.2 Qualitative longitudinal (QLL) interviewing	96
3.2.4.3 The pre-diagnosis period	99
3.2.4.4 A multi-perspective approach	100
3.2.4.5 Paired versus separate interviews when interviewing dyads	101
3.2.4.6 Exclusion and inclusion criterion	102
3.2.5 Sampling	102
3.2.6 Recruitment and attrition	105
3.2.7 Consent and capacity	107
3.2.8 Use of instruments	109
3.2.8.1 The NCCN Distress Thermometer (DT)	110
3.2.9 Quality in qualitative research	111
3.2.10 Reflexivity – where am I in the research process?	111
3.2.11 Transcribing	113
3.2.12 Analytic process	114
3.2.12.1 Coding	114
3.2.12.2 Constant comparative method	117
3.2.12.3 Memo-writing	117
3.2.12.4 Generating theory	117
3.2.12.5 Longitudinal analysis	118
3.2.12.6 Use of Computer Assisted Qualitative Data Analysis Software	121
3.2.12.7 Feedback of information to participants	121
3.3 Ethics of research with people with progressive life-limiting illness	122
3.3.1 Planning research with ‘vulnerable’ participants	123
3.4 Health and safety	124
3.4.1 Participant welfare	124
3.4.2 Researcher welfare	124
3.5 Summary of methods	125
Chapter Four: Participants and interviews	127
Participants	127
4.1 Time one (T1) – the period before a formal diagnosis is made	128
4.2 Time two (T2) – Starting treatment	130
4.3 Time three (T3) – Finishing treatment	131
4.4 Time four (T4) - Follow-up after approximately six months	131
4.5 Bereavement	132

4.6 GP Interviews	132
4.7 Other health, health-related and social care professional interviews	132
Chapter Five: The limbo before a formal diagnosis	135
5.1 Dramatic versus gradual presentation	135
5.1.1 Delays in reaching a diagnosis	138
5.2 Feeling better and euphoria after surgery	140
5.3 Uncertainty waiting for formal diagnosis	141
5.4 Limbo and emotional 'numbness'	142
5.5 Receiving a formal diagnosis	144
5.6 Summary	145
Chapter Six: Coping and adjustment	146
6.1 Emotional reaction	146
6.1.1 Distress, anxiety and worry	147
6.1.2 Distress over time	148
6.1.3 'Fearing the worst'	148
6.1.4 Anger and frustration	150
6.2 Moving forward and coming to terms with it	151
6.3 Coping strategies	153
6.3.1 Taking it as it comes	153
6.3.2 Living in the moment	154
6.3.3 Staying positive	155
6.3.4 Fighting spirit	157
6.3.5 Distraction and action	158
6.3.6 Comparison with others	159
6.3.7 Influence of past experiences	161
6.3.8 Denial and disavowal	161
6.4 Hope	164
6.4.1 Shifting hope	165
6.4.2 No hope	167
6.4.3 Realistic hope	168
6.5 Social and emotional support	168
6.5.1 Support from family and friends	168
6.5.2 Peer support	170
6.5.3 Professional support	171
6.6 Carers' concerns	172
6.6.1 Carers' skills	172
6.6.2 The strain of the caring role	174
6.6.3 Personality and behavioural changes	175
6.6.4 Respite	176
6.7 Summary	177
Chapter Seven: Information and communication	179
7.1 Lack of information	179
7.1.1 Information not tailored or specific enough	182
7.1.2 Dealing with medication	183
7.2 Desire for honest, clear and direct information	184
7.3 Ability to absorb information	185
7.3.1 Readiness for information	186
7.3.2 Reading between the lines	187
7.4 Importance of reassurance and positive information	188

7.4.1 Lack of reassurance.....	190
7.4.2 Communication style.....	190
7.5 Becoming experts.....	191
7.5.1 The internet as a source of information.....	193
7.6 Differences in approach to information.....	193
7.7 Summary.....	195
Chapter Eight: Managing and controlling illness	197
8.1 'Biographical disruption'.....	197
8.1.1 Work life disruption	197
8.1.2 Personal and social life disruption.....	198
8.1.3 Not being able to drive	199
8.1.4 Loss of independence or dignity.....	200
8.1.5 Disruption to carers' lives	201
8.2 Uncertainty about the future	202
8.2.1 Fear of recurrence	203
8.3 Physical and cognitive symptoms.....	204
8.3.1 Nausea and pain.....	205
8.3.2 Seizures and black outs.....	205
8.3.3 Hair loss.....	206
8.3.4 Fatigue and sleep disturbance	206
8.3.5 Memory and cognitive deficit.....	207
8.3.6 Mobility	207
8.3.7 Speech and language problems.....	207
8.4 Aspiring to 'normality'	208
8.4.1 Struggling to achieve normality	209
8.4.2 'New normal'	210
8.4.3 Adaptation to new abilities	211
8.4.4 Environmental adaptations.....	212
8.5 Finances and social circumstances	213
8.6 Practical issues	214
8.6.1 Transport	214
8.6.2 Parking	215
8.7 Summary.....	216
Chapter nine: Death, dying and existential issues.....	217
9.1 Facing death	217
9.1.1 How long have I got?	219
9.1.2 Preparing for and accepting death	220
9.2 Getting affairs in order.....	222
9.3 Preferred place of care.....	223
9.4 Palliative care.....	224
9.5 Spiritual and existential concerns	227
9.5.1 Religious faith	228
9.5.2 Why me?	229
9.5.3 Philosophy on life.....	231
9.5.3.1 Making the most of time you have	231
9.5.3.2 Shifting priorities.....	232
9.5.3.3 Orientation to the future.....	233
9.6 Dealing with the loss of a loved one after death	234
9.6.1 Feeling lost or isolated	234

9.6.2 Getting on with life	234
9.6.3 Keeping busy	235
9.7 Summary.....	236
Chapter Ten: Health professionals' views of glioma services.....	237
10.1 Hospital services	237
10.1.1 Specialist nurse service	239
10.2 Primary Care Services.....	240
10.2.1 GP Involvement	240
10.2.1.1 Diagnosis	241
10.2.1.2 Follow-up, monitoring and coordinating care	242
10.2.1.3 Symptom control	243
10.2.2 GP Skills	243
10.3 Shift from secondary to primary and community care	244
10.3.1 Improving coordination and continuity of provision	246
10.4 Palliative care services	247
10.4.1 Timely involvement of specialist palliative care	249
10.4.1.1 GPs' views on timely palliative care.....	251
10.4.2 Achieving appropriate care	252
10.4.3 Gold Standards Framework (GSF), Cancer and Palliative Care Registers	253
10.5 Out of hours services	255
10.6 Communication and information	257
10.6.1 Communication with patients and relatives	257
10.6.2 Communication between health professionals	258
10.6.3 Communication between secondary and community care.....	259
10.6.4 Improving communication and information	260
10.6.5 GPs views on communication	261
10.7 Holistic and existential/spiritual care.....	262
10.7.1 GPs' views on holistic patient care.....	264
10.8 Supportive care	265
10.8.1 GPs' views on Social and emotional support.....	267
10.8.2 Barriers to providing supportive care.....	267
10.8.3 Carer support.....	270
10.8.4 GPs' views on carer support	272
10.9 Summary.....	273
Chapter Eleven: Discussion.....	275
11.1 Reflections on methods: strengths and weaknesses	275
11.1.1 Recruitment and retention.....	275
11.1.1.1 Missing voices	276
11.1.2 Multi-perspective interviewing	277
11.1.2.1 Building comprehensive accounts	277
11.1.2.1 Paired vs. separate interviews.....	278
11.1.3 Longitudinal approach.....	280
11.1.3.1 Reflexivity and private vs. public accounts.....	282
11.1.4 Conducting research with 'vulnerable' people	283
11.1.5 Interviews with staff.....	284
11.1.6 Analysis	285
11.1.6.1 Managing large volumes of data.....	286
11.1.6.2 Use of the constant comparative method.....	286

11.1.6.3 Alternative approaches	287
11.1.7 Translation into practice	287
11.1.7.1 Generalisability	288
11.2 Reflections on findings, existing research and theory	289
11.2.1 Reaching a formal diagnosis	289
11.2.2 Coping and adjustment	292
11.2.2.1 Emotional reaction	292
11.2.2.2 Coping strategies	294
11.2.2.3 Hope	299
11.2.2.4 Social and emotional support	301
11.2.2.5 Carers' concerns	303
11.2.3 Information and communication	304
11.2.3.1 Lack of information	304
11.2.3.2 Tension between knowing and not knowing	305
11.2.3.3 Preference for positive and reassuring information and communication	306
11.2.3.4 Ability to absorb information	306
11.2.3.5 Individual differences in information preferences	307
11.2.3.6 Becoming experts	309
11.2.3.7 Information, communication and coping	309
11.2.4 Managing and controlling illness	310
11.2.4.1 Impact on life	310
11.2.4.2 Dealing with physical and cognitive problems	311
11.2.4.3 Fear of recurrence	313
11.2.4.4 Aspiring to normality	313
11.2.4.5 Practical and financial concerns	315
11.2.5 Death, dying and existential issues	316
11.2.5.1 Facing death	316
11.2.5.2 Community, primary and specialist palliative care	319
11.2.5.3 Spiritual and existential issues	320
11.2.5.4 Life after losing a loved one	322
11.2.6 Professionals' views on services	322
11.2.6.1 Hospital services	322
11.2.6.2 Primary and community care services	325
11.2.6.3 Specialist palliative care services	327
11.2.6.4 Out of hours services	328
11.2.6.5 Communication and information	329
11.2.6.6 'Total' care	330
11.2.6.7 Supportive care	331
11.3 Summary and integration of patient, relative and staff views	332
Chapter Twelve: Conclusions, future directions and suggested priorities	338
12.1 Future research and interventions	340
12.2 Suggested priorities for services	341
12.2.1 Possible developments to increase provision of support for patients and relatives	342
12.2.2 Possible developments to facilitate better information and recognition of information needs	343
12.2.3 Possible developments for services	344
12.3 Messages for future patients and carers	345

12.4 Suggested priorities for policy.....	346
12.5 Teaching and training	347
Glossary of terms.....	348
References	352
Appendices.....	374
Appendix One: Review methods and results.....	375
Appendix Two: Clinical depression and anxiety in brain tumour patients	382
Appendix Three: The role of support groups in supportive care	386
Appendix Four: Quality in qualitative research	389
Appendix Five: Evaluation of the National Comprehensive Cancer Network Distress Thermometer (DT) and DT tool.....	391
Appendix Six: Flowchart of recruitment process for neuro-oncology patients and their informal carer.....	394
Appendix Seven: Information sheets used in the study.....	395
Appendix Eight: Ethics approval letter.....	401
Appendix Nine: Recruitment letters for GPs and other health, health-related and social care professionals.....	404
Appendix Ten: Interview topic guides.....	408
Appendix Eleven: Consent forms.....	416
Appendix Twelve: List of health professionals.....	419
Appendix Thirteen: NVivo coding framework	420
Appendix Fourteen: Ethical dilemma when conducting multi-perspective interviews: a case study	425
Appendix Fifteen: Co-authored published journal articles evaluating multi-perspective and qualitative longitudinal methods.....	428

List of Tables and Figures

Table 1: WHO classification of gliomas	16
Table 2: Impact of supratentorial tumour on different areas of the brain	19
Table 3: Palliative care provision	26
Table 4: Longitudinal Qualitative Data Analysis	120
Table 5: Summary of patient and carer interviews conducted	128
Table 6: Participant details	134
Table 7: Databases searched	377
Table 8: Search terms used	377
Figure 1: Image of areas of the brain	18
Figure 2: The Holistic Dimensions of the Illness Experience	96

Chapter One: Introduction, rationale and aims

Primary malignant cerebral glioma is a devastating tumour with an overwhelming impact on the cognitive, physical, social, psychological and spiritual functioning of those diagnosed with the disease. This impact of glioma also permeates deeply into the lives of those along side the person with the diagnosis. This thesis explores the experience of glioma for patients¹ and their loved ones over the course of their illness from before formal diagnosis to death and bereavement, capturing the holistic dimensions of the illness.

1.1 Malignant cerebral glioma

Brain tumours are relatively rare, making up around 2% of all cancers diagnosed in the UK each year (McKinney, 2004). There are around 450 new cases of tumours of the central nervous system (including brain) in Scotland each year, with this figure expected to increase (Scottish Executive, 2004). Gliomas constitute over half of all primary brain tumours in adults, with some research quoting figures of over 90% (McKinney, 2004, Grant, 2004)). Gliomas are more common in men (male:female ratio of 1.5:1) and the incidence rises with age (McKinney, 2004). High-grade tumours anaplastic astrocytoma, anaplastic oligodendroglioma (WHO grade 3) and glioblastoma multiforme (WHO grade 4) account for the majority of all gliomas (Gupta and Sarin, 2002), with the rest consisting of lower grade tumours Pilocytic astrocytoma (WHO grade 1), astrocytoma and oligodendroglioma (WHO grade 2) as well as

¹ I have referred to glioma 'patients' throughout this thesis for ease. However, I considered each individual as a person 'with a brain tumour' such that they were not defined by their disease.

ependymomas, mixed gliomas and a range of other rare types of gliomas (See table one)(World Health Organisation, 2007). Prognosis for gliomas is poor, with median survival for patients ranging from 1-5 years depending on the histological grade of the tumour, with median survival for patients diagnosed with a glioblastoma multiforme at less than one year (Chang et al., 2005). Variance in survival is dependent on age and performance status; location of the tumour; treatment options; treatment effects; and surgical potential. A moderate survival advantage can be obtained for patients who are in a good state of health at the time of diagnosis and undergo complete resection of their tumour compared with those in poor health and not eligible for surgery (Rampling et al., 2004).

Oligodendroglial cell tumours	Astrocytic cell tumours
Oligodendroglioma (WHO grade 2)	Pilocytic astrocytoma (WHO grade 1) Astrocytoma (A)(WHO grade 2)
Anaplastic oligodendroglioma (WHO grade 3)	Anaplastic astrocytoma (AA)(WHO grade 3) Glioblastoma multiforme (GBM)(WHO grade 4)

Table 1: The WHO classification of the most common gliomas (WHO, 2007)

Glioma is a supratentorial tumour of the glial cells, occurring in different locations of the brain with varying impact on function and ability. Glioma is an infiltrative tumour that is difficult to treat. It grows at different speeds and spreads locally within the confines of the skull, creating pressure effects as well as impacting on eloquent areas of the brain. Each glioma patient is affected differently and is subject to general effects of the tumour, localised effects dependent on the specific location of the tumour and side effects from treatment and medication. Raised intracranial pressure exacerbates the mass effect and can cause headaches and seizures as well as impacting on other cognitive and physical function. Patients are often dependent on steroids to control the pressure on the brain caused by the tumour as well as anti-epileptic medication to

control seizures. Steroids can cause a major change in appearance for patients with weight gain and swelling. The presence of seizures automatically disqualifies patients from driving and they often cannot work or be left alone. Patients can also be susceptible to venous thromboemboli and therefore may need to take anticoagulants. Patients also have to deal with surgery, radiotherapy and chemotherapy, which can leave them suffering from fatigue and somnolence, as well as long term effects that are becoming more prevalent as patients live longer (Imperato et al., 1990). In addition to dealing with physical and cognitive symptoms of the disease, patients and their families also have to come to terms with their diagnosis and prognosis, with major implications for psychological adjustment and coping. Figure one shows the different areas of the brain and the associated functions that can be impaired by the presence of a tumour or its surrounding oedema.

Carers² have to deal with looking after their loved one, often at the expense of their job thus causing financial strain. Moreover, they have to watch their loved one deteriorate and in many cases personality and behavioural change are the source of real distress for family members of glioma patients (Davies and Hopkins, 1997a, McNamara, 2008).

² I have used the terms carer, caregiver, spouse, and relative interchangeably throughout this thesis. The people sharing the experience of a glioma or other illness with the person with the diagnosis may not have seen their role as that of carer, particularly not when the person experienced a stable period where they were able to function in their daily lives. However, the term has come to be used commonly to describe those who go on to adopt an informal caring role in looking after the person closest to them whether it be in a supportive role or a more instrumental role.

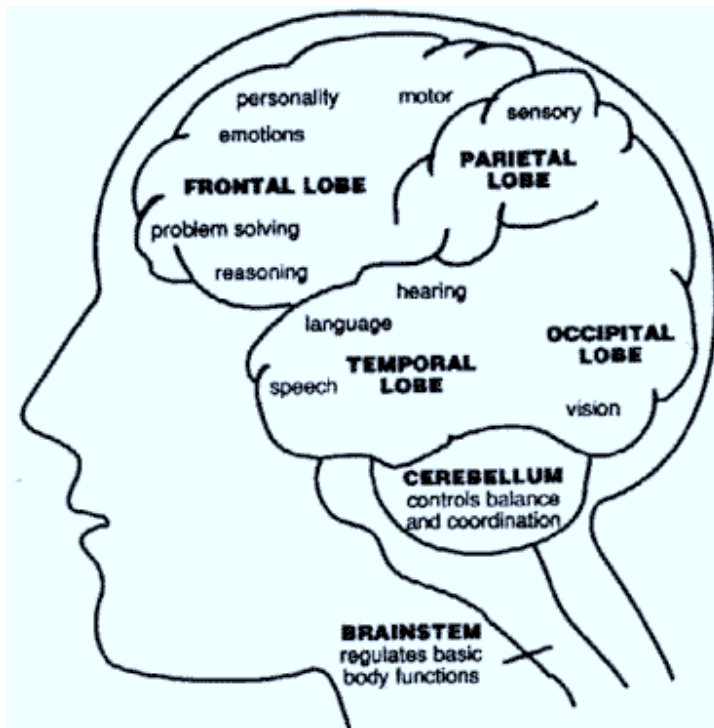


Figure 1: Image of areas of the brain. Downloaded from www.state.sc.us/ddsn/pubs/hinjury/sec3.htm on 28.08.08

There is wide variation in symptoms as a result of the tumour depending on where it is located. Gleason *et al* report on two sets of symptom clusters in their randomised controlled trial of newly diagnosed brain tumour patients receiving radiotherapy – language clusters and mood clusters. Language clusters impact on reading, writing, and finding the right words and a mood cluster includes feelings of sadness, anxiety, and depressed mood (Gleason *et al.*, 2008). However, this does not account for the crippling physical symptoms. Faithfull *et al* report on the symptom profile of 39 patients diagnosed with a glioma who had been referred for palliative care as compared with a more general palliative care population reported on in a study by Potter *et al* (Potter *et al.*, 2003, Faithfull *et al.*, 2005). In Faithfull's study, symptoms displayed included 62% headaches, 62% hemiparesis, 56% suffered seizures, 51% confusion and 44% fatigue. This symptom profile differed somewhat from that of the

general palliative care population where the five most common symptoms were pain, anorexia, constipation, weakness and dyspnoea (Potter et al., 2003). It has been suggested elsewhere in the literature that the symptom profile and its impact is distinctive and more severe in glioma patients than in other forms of cancer (Lidstone et al., 2003, Taillibert et al., 2004).

Table two shows the position of brain tumours in certain areas of the brain and the symptoms that might impact upon patients' and loved ones' lives.

Position of tumour	Symptoms
<u>Frontal lobe</u>	Changes in personality Swearing or behaving in a way that you normally wouldn't (loss of inhibitions) Losing interest in life (apathy) Difficulty with planning or organising Being irritable or aggressive Weakness in part of the face or on one side of the body Difficulty walking Loss of sense of smell Problems with your sight or speech
<u>Temporal lobe</u>	Forgetting words Short term memory loss Fits associated with strange feelings, smells or déjà vu
<u>Parietal lobe</u>	Difficulty speaking or understanding what is said to you

	Problems with reading or writing Loss of feeling in part of the body
<u>Occipital lobe</u>	Sight problems or loss of vision on one side
<u>Brain stem</u>	Poor co-ordination Drooping eyelid or mouth on one side Difficulty swallowing Difficulty speaking Seeing double

Table 2: Impact of supratentorial tumour on different areas of the brain. Downloaded from <http://www.cancerhelp.org.uk/help/default.asp?page=5017#common> on 28.08.08

1.2 Management of glioma patients

Service provision varies across the UK although the core of standard treatment is the same. The typical care pathway for a patient presenting to the centre where the research study is based would be as follows:

1. The GP or referring clinician from a district general hospital (DGH) or emergency department refers the patient to the department of clinical neurosciences (DCN) with a provisional diagnosis of brain tumour identified via imaging (CT or MRI scan).
2. Further imaging may take place at DCN to confirm this.
3. Patients are usually given dexamethasone steroids pre-operatively to relieve intracranial pressure caused by the tumour and any swelling around it, alleviating symptoms for the patient.
4. In most cases, scans will be reviewed at a multi-disciplinary team (MDT) meeting to discuss the best course of action.

5. At this point patients will undergo surgery to perform a biopsy of tissue and a partial or total resection of the tumour where possible.
6. Some patients who are eligible may have a carmustine implant inserted into the brain cavity where the tumour was removed. This is a form of chemotherapy delivered directly to the tumour site. In some cases surgery of any kind is not possible, depending on the location of the tumour.
7. Following surgery, a treatment plan will be decided for each patient. This could involve a radical six weeks course of radiotherapy in 30 fractions delivered at a dose of 60Gy or an alternative palliative course of two weeks in six fractions giving 30Gy. Patients may be eligible for concomitant and adjuvant chemotherapy if they are of a certain age and fitness with an appropriate performance rating. This treatment regime is a recent development since the National Institute for Clinical Excellence (NICE) guidelines on use of temozolomide, a chemotherapy drug, were published and implemented (NICE, 2007). At the time the study began it was not that common to give concomitant and/or adjuvant temozolomide chemotherapy.
8. Upon recurrence of the tumour, treatment options vary considerably dependent on how well the patient is doing. In some cases further surgery and palliative chemotherapy are an option.

1.3 Improving treatment and care for glioma patients

There have been attempts, including research interventions and government reports, to improve care for glioma patients over the last decade. Much of the research published in this area is aimed at standardising and improving the medical aspects of care (e.g. Gupta and Sarin, 2002). A survey of all UK clinical oncologists showed a lack of standard protocol with variation in practice across the UK in terms of surgical, clinical

and medical treatment of the disease (Gerrard et al., 2003). Little is known about provision of psychosocial care for this patient group.

1.3.1 Best practice in the management of gliomas

An overview of the current best practice treatment and overall management of glioma suggests that treatment has not significantly improved survival for decades (Rampling et al., 2004). As mentioned in the previous section, recent developments in chemotherapy have given rise to a modest increase in survival (Stupp et al., 2005). Optimal treatment for gliomas involves maximal resection followed by radical radiotherapy and concomitant and adjuvant chemotherapy. However, not all patients are candidates for this treatment dependent on the location of the tumour, their age, fitness and performance rating. A recent Italian study (Minniti et al., 2008) shows that use of concomitant and adjuvant chemotherapy also has some effectiveness in older patients with good performance ratings while contrasting research suggests that toxicity is more significant in older patients (Sijben et al, 2008) , suggesting that the ways in which eligibility is assessed and the full impact of these treatment developments remain to be seen.

Genetic factors have also been found to influence survival. Patients with 1p19q gene deletion have improved survival and have a better response to chemotherapy and radiotherapy. MGMT promoter hypermethylation is also associated with enhanced survival (Rampling et al., 2004, Krex et al., 2007). Advances in the genetic classification of gliomas has implications for the conventional WHO grading system and the ways in which tumour types are identified and treated. Advances in medical treatment continue with novel agents introduced into standard treatment being examined in clinical trials.

1.3.2 Psychosocial and supportive care

Despite recent advances, the treatment of glioma is still not curative. Treatment is essentially palliative and thus adequate supportive services must be available (Junk, 2004). This also means a focus on the quality of life of patients suffering with glioma. It is recognised that emphasis on psychosocial and supportive care issues is vital given the terminal prognosis of glioma and the devastating impact of the disease e.g. (Curren, 2001, Catt et al., 2008, Keir et al., 2008a). Grossman and Batara assert that research into the psychosocial and supportive care issues facing glioma patients and their families is critical to improve quality of life (Grossman and Batara, 2004).

In 1997, Davies and Hopkins produced guidelines for the Royal College of Physicians aimed at improving care for people diagnosed with a glioma (Davies and Hopkins, 1997b). This report introduced psychosocial issues to the agenda, including breaking bad news and considering patient and carer support needs. As well as addressing the best treatment options for this patient group, Davies and colleagues also considered the individual patient's support needs and those of their families. For example, it was suggested that health professionals should record the immediate concerns of the patient at diagnosis; consider the impact of the disease on various elements of the patient's life including work, social life, child care, household chores, finances, cognitive ability and personal care; and continually monitor psychosocial needs. Moreover, the authors recommend that patients should have nurse support at the earliest opportunity. Despite this new agenda, there is little evidence to suggest that consideration of psychosocial issues have, as yet, been fully integrated into best practice as a standard dimension to patient care.

A 2006 report published by NICE is aimed at improving outcomes for patients with brain and other tumours of the central nervous system (NICE, 2006a). A Scottish

equivalent of this report is currently lacking, but the NICE guidelines have been used to shape services in Scotland. This report brings the supportive needs of brain tumour patients to the fore with a focus on information and communication issues and the standardisation of patient care. The key recommendations include:

- All patients' care should be co-coordinated through a designated multi-disciplinary team (MDT)
- All patients should have face-to-face contact with healthcare professionals to discuss their care at critical points in their care pathway, and be provided with high quality written information to support this
- All patients should have a clearly defined key worker
- Patients should have ready access to specialist care services as appropriate
- Palliative care specialists should be core members of the neuroscience MDT and of the cancer network MDT
- Cancer networks should ensure that clinical trials on brain tumours carried out by the National Cancer Research Institute (NCRI) are supported and patient entry into these studies actively monitored

Source: <http://www.nice.org.uk/guidance/index.jsp?action=byID&o=10905> accessed 16.09.09

The NICE report also recommends communications training for health professionals and that they should discuss prognosis with patients so they can participate fully in the decision-making process. Although there have been a number of patient-based accounts published in the literature (see chapter two), these remain limited.

Conducting further research into patient perspectives will enrich understanding of the pertinent issues for those living with a brain tumour and feed into future guidance on designing services according to patient and families' needs.

1.3.3 Palliative care services

Although there are treatment options available to those diagnosed with glioma, unfortunately these are not curative. Glioma patients can therefore benefit from palliative care services. Often patients can be well for a long period of time and function well in various aspects of their lives. These patients and their families may not feel that they require palliative care services. However, according to a broad definition of what palliative care can offer, brain tumour patients and those closest to them can benefit.

The World Health Organisation defines palliative care as follows:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

(World Health Organisation, 2002)

Table three gives details of the kind of services and support that palliative care can offer.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Table 3: Palliative care provision. Source: WHO (2002)

<http://www.who.int/cancer/palliative/definition/en/> accessed 8.12.2008

A recent review of palliative care services in Scotland identifies the need for reliable specialist palliative care across Scotland as provision and access is currently variable (Audit Scotland, 2008). For example, at the time the report was published, only one NHS board in Scotland had implemented the Liverpool Care Pathway, a protocol to ensure standardised good quality of care in the last days or hours of life, in acute and community hospitals. Furthermore, this report highlights support needs such as appropriate access to out of hours services and psychological support to deal with the emotional aspects of dealing with a life-limiting illness. Given the devastating

prognosis and crippling symptoms of a high-grade glioma, appropriate services to meet these support needs are paramount.

Other developments in UK palliative care services include the establishment of “supportive and palliative care registers” in primary care, as part of the Quality and Outcomes framework (Department of Health, August 2004). All patients with glioma are candidates for this register and are subject to increased support as is set out in the NICE Guidelines and Scottish end of life care plan. The Gold Standards Framework (GSF) is another initiative relevant to glioma patients receiving primary palliative care, now incorporated into the NHS End of Life Care Plans for England and Scotland. The GSF guidance, first piloted in 2001, providing a structure for provision of care for people in the last year of their life (Department of Health, 2001). Although the GSF has been variably implemented across the UK, over 90% of practices now adopt it at least at Level 1 to organise such care to all cancer patients (Department of Health, October 2007). The Department of Health has also published a recent End of Life Care Strategy aimed at improving the provision and coordination of care for people in the last year of life and enabling them to have a ‘good death’ which encompasses the Liverpool Care Pathway and other end of life care tools (Department of Health, 2008). In Scotland, services have come under scrutiny and an action plan entitled ‘Living and Dying Well’ has been developed to improve both generalist and specialist palliative care (Scottish Executive, September 2008).

1.3.4 Specialist nurse support

The advent of the neuro-oncology specialist nurse was considered an important step in improving care for brain tumour patients (Davies and Hopkins, 1997a). Guerrero and McNamara both give an overview of the role of the neuro-oncology nurse, highlighting

the involvement of nurses in the supportive care of glioma patients and their families (Guerrero, 2002, McNamara, 2007). A nurse-led telephone clinic has been introduced in certain parts of the UK to follow up glioma patients and has been evaluated as an acceptable alternative to hospital follow-up, and a way of providing patients and carers with a point of contact to voice any medical or emotional concerns and receive support, thus improving patient care. Neuro-oncology nurses, however, are not standard across the UK and so there is geographical variation in the service provided.

1.3.5 Other sources of support for glioma patients

There are a number of charitable organisations working to improve the lives of those suffering with brain tumours and their families. These include Brain Tumour UK, Brain Tumour Action and the Samantha Dickson Brain Tumour Trust. These charities provide a forum for patient and carer support groups and fundraising activities; an interface between patients and professionals at conferences and other events and funding for all types of research to improve service delivery and patient care. The work of more general cancer charities such as Macmillan and Cancer Research UK are also of benefit to glioma patients.

The Scottish Adult Neuro-Oncology Network (SANON) has been running for three years as a managed clinical network that unites the centres for neuro-oncology across Scotland, standardising and improving care. The network aims to bring together professionals, patients and the voluntary sector. This thesis provides a rich theoretical understanding of patient experience as an evidence base for such networks.

1.4 Understanding the illness experience

This thesis places emphasis on understanding the illness experience from the perspective of patients and their families in order to discover the issues that are pertinent for people as their illness progresses. A sizeable medical sociology and health psychology literature exists exploring the construction of the illness experience and how our understanding of it has shifted over the years (e.g. Leventhal et al., 1997, Kleinman, 1988). Our approach to understanding illness and a person's individual and shared experience of it is shaped by how we see the social world in which we live (see chapter three for more discussion on theoretical perspectives).

1.4.1 Moving towards patient-centred care

In the 1950s and 60s, the illness experience was understood in terms of the Parsonian sick role, the patient became a passive recipient to medical care and the person they were was lost (Parsons, 1951). Over the next few decades, there was a marked paradigm shift in our framing of the illness experience to one of the 'empowered patient'; the patient who sought to rediscover themselves and take control of their illness. Salmon examines how the 'empowered patient' has become a mainstream concept in medicine and can be manipulated by the healthcare system. Salmon argues that the concept of the empowered patient may not necessarily be on the patient's agenda but has become a narrative that the public wants to hear (Salmon and Hall, 2003, Salmon and Hall, 2004).

Rier, in his discussion of the 'missing voice' of the critically ill, suggests that when a person is critically ill, they may be happy to embrace the sick role rather than be an active agent in their destiny (Rier, 2000). Rier felt that in his own situation, the fact that

information was withheld from him allowed him to retain hope and in doing so aided his recovery. As Rier posits,

“The lifesaving potential of selective disclosure is easily neglected in today’s climate of consumerism, empowerment, informed consent and the right to know”. [Rier, 2000: 82]

Later discussion based on the findings of the present study will develop this theme in chapter 11.

The phenomenon of the empowered patient sits within a wider cultural and political context that has evolved over decades but has yet to be fully realised. A 1989 White Paper ‘Caring for People’ led to the publication of the 1990 NHS Community Care Act and marked the culmination of a growing rhetorical emphasis on service user involvement and empowerment which started with user groups formed as far back as the 1970s (Kendall, 1999).

The philosophy of understanding and giving weight to patient experience can also be traced back to the hospice movement of the 1960s founded by Cicely Saunders (Saunders, 1981), marking a shift away from traditional biomedicine. The traditional paternalistic model where the health professional would dictate the course of the illness gave way to a shared ‘partnership’ approach. Saunders developed the modern hospice movement on a foundation of ‘total care’ of patients, thus accounting for dimensions of their illness experience beyond the physical³.

³ Vivat (2006) discusses Saunders’ approach to patient care in her exploration of working practices in a West of Scotland hospice. VIVAT, B. (2006) The whole and the parts: spiritual care in a West of Scotland hospice. University of Edinburgh.

1.4.2 Telling your illness story

Frank, a sociologist, conceives of the experience of illness as embodied by the individual through their telling of their illness story (Frank, 1995). One's story is transitory, a shared construction with the listeners of the story, bound by what they want to hear and the contextual surroundings and cultural influence. Telling one's story allows the teller to make sense of their experience through their narrative. Frank provides a series of narrative forms for understanding common illness stories returned to in the discussion chapter (Frank, 1995).

Enabling people to reclaim their story and have a voice fitted well with the aim of this study: to allow people with a brain tumour diagnosis and their loved ones to tell their story in their own words. It also allowed consideration of the contextual influence on a person's story, how their past experience and position in a particular place and time had power in the development of their story. The concept of the illness narrative was reflected in the chosen qualitative method. The longitudinal approach allowed the dynamics of the illness narrative to unfold over the course of the illness.

Qualitative research mirrors patient-centred care, where participants give their views and influence the development of services to meet their needs. However, in line with Frank's illness narratives, the act of analysing patients' stories leads to a second level of interpretation. Inevitably, some elements may be 'lost in translation' as narratives become the researcher's story.

1.5 *Setting the research agenda*

An overview of recent research and initiatives has shown that various aspects of care beyond the physical for both patients and their families need to be acknowledged and

integrated into health care provision in line with the patient-focussed ethos of care, thus putting the lived experience of glioma patients and their families firmly on the research agenda. As the evidence presented in this chapter has shown, improvements in the care of patients diagnosed with a glioma and their families has to date focused on treatment and survival despite increasing recognition of and greater emphasis on psychosocial support. Further in-depth research exploring the psychosocial issues of the experience of the patient with a malignant glioma will help illuminate this dimension of patient care further and help improve supportive care for this patient group, which have been highlighted as a research priority (Perkins et al., 2007). In the current study, I sought to identify areas where improvements to patient care could be made by helping the voice of glioma patients and their loved ones to be heard, together with those professionals providing care.

1.6 Aims and objectives

The aim of this study was to give the opportunity to the patients and their families to describe their experiences of the illness journey and voice their own concerns and unmet needs, and their own suggestions for improving services. Rather than impose rigid research questions, this study was an exploration of peoples' holistic experience of pathway to diagnosis, receiving a formal diagnosis, staging and planning, treatment, follow-up, disease progression, further treatment, palliation and end of life care. This study explored the place of spiritual and existential issues and support as well as the perceived role of multi-disciplinary palliative and supportive care.

Summary of aims:

- To understand better the experiences of being diagnosed and treated for malignant cerebral glioma for the patient and their family.

- To identify dimensions of the illness experience beyond the clinical treatment for the disease.
- To examine how these experiences and needs changed over time as the patient and their relatives progressed through the illness journey.
- To ascertain the extent to which these dimensions were recognised and supported through health service and other interventions, highlighting areas of unmet need in the illness journey.
- To gain suggestions from patients and their families about how their holistic care might be improved throughout the course of the illness.
- To explore the views of professionals involved in the care of this patient group about their unmet patient needs and how these can be met.
- To identify ways of improving care and make recommendations (based on patient, carer and professional views) for clinical, policy and educational development.
- To identify further research specifically targeted to improve patient and family care.

Chapter Two: Review of the literature exploring the experience of a malignant brain tumour

Introduction

This chapter presents a review of the literature exploring the background to understanding people's experience of glioma. The aim of this review was to identify, evaluate and synthesise the empirical and theoretical literature exploring the lived experience of a malignant brain tumour for the patient and their loved ones. In particular, I was interested in the psychosocial issues which patients faced beyond the physical demands of glioma. This review employed some of the techniques of systematic reviewing in order to provide structure and clarity to the process and to ensure that a broad range of articles were retrieved.

2.1 Living with glioma – defining the review agenda

No coherent body of literature exists to shed light on the experience of living with glioma for patients and their families. The concept of 'living with glioma' was defined here as the experience of the patient and their family from the period of reaching a diagnosis through treatment, follow-up, stable disease, progression, decline and the terminal phase. Living with a glioma is complex and multi-dimensional, encompassing physical, psychological, emotional, social, spiritual and practical dimensions in addition to interaction with staff and services in the health and social care system. Gliomas can often result in a very fast decline, with patients' needs changing rapidly over time. The demands on the patient's carer will also change rapidly; in turn affecting carers' own health and needs.

2.2 *The literature*

The literature on cancer and other chronic illnesses is vast and diverse, including qualitative and quantitative empirical work and theory; covering interventions, randomised-controlled trials, in-depth interview studies, ethnographies, observational work, descriptive studies, sociological inquiry, psychological inquiry, reports, theoretical pieces, editorials, evaluations, and government policy documents. The literature on brain tumours sits within this complex network of articles, and the qualitative brain tumour literature a further subset; thus a very broad literature base informed this enquiry.

My initial aim was to identify literature specifically relating to glioma and other brain tumours. In particular, the literature concerning issues relevant to living with a glioma beyond treatment of the physical disease. The search for literature included both quantitative and qualitative papers, as well as theses, theoretical papers, editorials and discussion pieces. Particular weight was given to in-depth qualitative articles that explored individual experience of brain tumours. The broader cancer and palliative care literature was included where appropriate to further inform the more general issues raised in relation to living with a life-limiting illness. Due to the sheer volume of articles, it was necessary to include a selection from within the broader literature.

2.3 *Review methodology*

Due to the exploratory nature of the review, it was not possible to design it according to conventional systematic review methodology for such a diverse and complex body of literature consisting of predominantly qualitative research. Variations on review methodology for more diverse literature have been developed and difficulties outlined

e.g. (Britten et al., 2002, Dixon-Woods et al., 2004a, Dixon-Woods et al., 2006). For example, it was impossible to specify in advance the categories under which the findings would be summarised in this review. Qualitative literature is notoriously more difficult to identify when searching literature databases, and the effectiveness and efficiency of searching databases alone has been questioned (Greenhalgh and Peacock, 2005).

An integrative review of the evidence on living with a glioma was conducted. The review aimed to identify papers exploring the lived experience of glioma patients, psychosocial and supportive care issues for this patient group, and for cancer patients more generally, where relevant. A number of key databases were searched along with key authors, reference chaining and grey literature according to a list of search terms developed. Articles were screened for relevance and quality. Finally, a selection of the remaining articles were included in the review to give an overview of relevant issues. (See Appendix One for full details of the review methods and results)

2.4 Findings

A selection of papers was included, chosen to cover a broad range of concepts from the large literature relevant to the study. The selected papers included general papers on health and illness, specific papers about cancer and papers reporting specifically on glioma. Attempts have been made to categorise the main findings in the literature including articles where there was overlap between topics and different language used to describe similar phenomena. Articles are reported in their most relevant category. Categories include: reaching a diagnosis; living with a glioma; psychological issues; information and communication; supportive care; quality of life; carers' needs; existential concerns and palliative care.

2.4.1 Reaching a diagnosis

Patients' early illness experiences have been sign-posted as highly significant in predicting future adaptation to their illness (Weisman and Worden, 1997).

Understanding the pathway to diagnosis is therefore crucial in developing services to meet patient and carer needs at this time and warrants exploration. This section reports on articles looking at pathways to diagnosis specifically for malignant brain tumour patients.

Salander *et al* interviewed 28 high-grade glioma patients (18 male, 10 female; aged 18-70 years) and their spouses as part of a wider study (Salander et al., 1999). It is not entirely clear how the data were analysed but the authors applied a 'thematic structure' to their data. 'Trigger symptoms' that prompted people to consult a physician (20 out of 28 first contacted primary care) were headache; seizure/ falling; motor or sensorial dysfunction; and mental dysfunction. Patients, spouses and physician factors were all reported as obstacles to medical care: For patients, having 'less alien symptoms', loss of judgement or ability to act, and avoidance all delayed help-seeking. In nearly half of cases, spouses were the ones who initiated contact with a doctor and so cases of passive spouses or spouses adapting to the patient's symptoms delayed this contact; thus an important role also identified in the general cancer literature (Leydon et al., 2003). Salander *et al* suggest that on occasion physicians can be inflexible and unwilling to accept that their initial diagnosis might not be correct, delaying further investigation. Patients and spouses also reported that they felt their physicians' own views mediated the course of action taken.

Edvardsson and colleagues explore the onset of symptoms and the pathway to diagnosis in 27 low-grade glioma patients (18 male, 9 female; aged 23-79 years) (Edvardsson et al., 2006). They excluded patients who were not able to remember their

experience clearly and also carried out the interviews retrospectively. Twenty patients described a rapid onset (defined as over a period of days or months) of symptoms while for the remaining eight, onset was more gradual (over a period of years). Seizures were the most commonly reported symptoms followed by headache, vomiting and loss of vision. Medical care was sought immediately for the majority of patients. As in Salander's study, caregivers played a pivotal role in help-seeking. Symptoms with a prolonged onset were the same as rapid onset but also included difficulty orientating oneself; personality changes, sensory loss, memory loss, racing thoughts and tinnitus, and were explained away by patients with alternative diagnoses. Participants in this study reported that concerns were dismissed; that they were treated badly and not involved in decision-making about their care. This resulted in disappointment and angry at delays and misdiagnoses with repeated visits to the doctor; echoing the wider literature (Grbich et al., 2000, Leydon et al., 2003). Overall, this evidence suggests that patients' encounters with those most involved in their care can dictate their adaptation to their illness, as reported elsewhere (e.g. Friedrichsen et al., 2000).

There was a lack of prospective or 'real-time' accounts of the pathway to diagnosis for cancer patients, although there are some examples e.g. (Lepola et al., 2001, Wyness et al., 2002). By interviewing brain tumour patients in the period before they were given a confirmed diagnosis, I have highlighted the issues prospectively and identified how these varied from retrospective accounts. The differences between high and low-grade glioma patients will be returned to in the discussion chapter 11.

2.4.2 Living with a brain tumour

There have been a small number of studies looking at the experience of living with a brain tumour. Those studies with a more specific focus have been included in

subsequent relevant sections of this review. A selection of key papers looking at the overall brain tumour experience were included in this section to better understand the generic issues.

Wyness *et al* analysed a series of narratives from 18 patients (with a range of brain tumour diagnoses) in the pre-operative phase and 15 carers (29 interviews) in a Canadian hospital (Wyness et al., 2002). 13 questionnaires were also completed. A further 24 pre-discharge interviews were conducted with 13 patients and 11 carers and all were analysed as case studies. Detection of a brain tumour and facing surgery was associated with profound fear, anxiety and distress which still resonated with participants post-surgery and at follow-up. Elsewhere, another study looking prospectively at the pre-surgery phase showed anxiety and desire to return to normal at this time (Lepola et al., 2001). Patients sought reassurance, some felt that knowing was not always better than not knowing; and there were individual differences in approach to and absorption of information. Establishing supportive relationships facilitated information seeking and reduced anxiety, distress and worry. While Wyness *et al* provide a valuable insight into this time period that has not been studied prospectively elsewhere in this patient group, I aimed to add an overview of experience of glioma *throughout* the course of the illness.

Davies, Clarke and colleagues in London have produced a series of articles exploring symptoms, treatment experience, and psychosocial and supportive care issues for people with a diagnosis of glioma (Davies and Hopkins, 1997b, Davies and Hopkins, 1997a, Davies et al., 1996a, Davies et al., 1996b, Davies and Bannon, 1999, Davies and Higginson, 2003, Davies et al., 2003, Davies and Clarke, 2004, Davies and Clarke, 2005). A number of important findings are reported. A study of 105 patients explored experience over time, recruiting at diagnosis, after radiotherapy and after recurrence (Davies et al., 1996b). Awareness of prognosis varied considerably, with only 25% of

patients and 67% of relatives fully aware, although awareness developed over time. Relatives generally wished to shield patients from knowledge of prognosis. Aware patients were significantly more likely to be distressed and (in line with this) relatives were more likely to be distressed. It is possible, however, that patients chose not to attend to their awareness in order to minimise distress, a concept returned to in chapter 11. Although interviews followed the same participants, the authors did not explicitly explore changes in experience over time or focus on the period before or immediately following diagnosis. In my own study, I developed this dimension of understanding in exploring people's experiences as their illness progressed.

As previously reported, Davies *et al* published guidelines to improve care for people with malignant glioma, providing important insights into understanding ways of improving services (Davies and Hopkins, 1997a, Davies and Bannon, 1999). Guidance on the supportive management of people with a diagnosis of glioma included: timely, sensitive and clear information at critical time points; information for relatives; a palliative approach with appropriate early referral; nurse specialist involvement; rehabilitation, support and counselling; better liaison with primary care and support to manage glioma at home; assessment of holistic support needs; engagement with allied health and social care professionals; development of a strategy for information and communication; governance of good quality research.

Wideheim *et al* in Sweden reported on families' perspectives of high-grade glioma. Fifteen interviews were conducted (three patients, five relatives) at two stages: after surgery/diagnosis and three to six months later (Wideheim *et al.*, 2002). Patients had mixed reactions at diagnosis from denial to recognition of death. Although happy overall, patients reported a lack of information in the weeks between diagnosis and surgery, leading to anxiety (suggesting different management of glioma to the UK centre in which this study was based – see chapter one). Patients felt limited in their

daily lives due to fatigue and not being able to drive. Support from family and friends were valued highly. Relatives were extremely distressed, uncertain and felt powerless to control the future, a finding mirrored elsewhere (Strang and Strang, 2001). They wanted to protect the patient from the reality but had significant information needs themselves about chances of survival, treatment and recurrence, and did not feel informed or reassured. Relatives' own lives were changed, often giving up work as they didn't want to leave the patient alone. Relatives saw their role as key but reported problems managing the illness with effects on their own physical and mental health. Relatives also valued support from friends, family and professionals. Over time, relatives tried to keep busy and get back to a normal life, such as returning to work. Hope was created by having faith in treatment; believing the patient would defy the statistics; information from professionals; and assurance when the patient was feeling well. Relatives' encounters with staff at this stage were positive and reassuring and information given about what to expect was adequate. Information was realistic but gave some positive facts to instil hope, a communication style valued enormously. When communication was pessimistic, next of kin found that the words 'stayed with them' and caused distress. The authors called for further research covering the entire course of the illness to understand the family's perspective, which the present study has addressed.

Salander and colleagues in Sweden have contributed immensely to the qualitative studies on experience of brain tumours and gave important background for the present study. For example, a serial interview study with 28 patients (20 male, 8 female; mean age 54 years) with a high-grade glioma and their spouses added detailed knowledge of patients' 'life situations' from diagnosis to death (Salander et al., 2000). Interviews were conducted after surgery, after radiotherapy, 5 months after radiotherapy and bereavement interviews one month after death. People's experiences were characterised according to two distinct concepts: 'time of everyday life' and 'time of disease'. Time of

everyday life described a degree of continuity in work, family, spare time and social life as it had been. Time of disease covered times of preoccupation with illness and its treatment, disrupting everyday life. 36% of patients (n=10) experienced time of disease after their primary treatment but did not necessarily experience loss of well-being or poor coping, although this was the case for some. 64% (n=18) people experienced time of everyday life, with a median time of 9.5 months before time of disease took over. As the authors argue, time of everyday life was still possible even when a person's disease had progressed. Patients aged over 70 or with poor performance status were excluded from participation and time of disease may have been more prevalent in this group of patients. Moreover, time of everyday life was not assessed according to patient and spouse perceptions alone, where adaptation to illness counts for a lot. It also became clear from the description of findings that even those experiencing time of disease attempted to engage with time of everyday life, and so the two concepts are not entirely mutually exclusive. Nevertheless, this characterisation gives a valuable insight into the survival time of high-grade glioma and has value for clinicians in understanding that all is not lost even with a poor prognosis.

Another paper reports how patients and their spouses struggle to cope with the impact of diagnosis of glioma (Salander and Spetz, 2002). Varying knowledge of prognosis is found to impact on the relationship between the patient and their spouse, with some people forming a joint platform while others drift apart and coped differently. On the whole, spouses wanted more information, particularly in relation to facts about prognosis, although they were keen to go along with what their partner wanted. Patients sought information about treatment processes, questions about appointments or specific issues rather than broader concerns or details about their illness. Awareness did not always translate into open communication about one's illness and prognosis. Those spouses who shouldered the burden of awareness alone found keeping up the pretence a strain. Sometimes there was a mutual acknowledgement of the facts without

discussion or subtle implicit references to impending death. It is unclear from the reports of Salander *et al*'s studies whether patients had been given a confirmed diagnosis at the time of the first interview and so there is not such a focus on the pre-diagnosis period.

In my own study, I will build on what is known from Salander's work and use a similar longitudinal technique but a different approach, with attention to the period before a confirmed diagnosis has been reached and also probing other topics such as information and communication and spiritual and existential concerns that were not set out in Salander's study, but appeared to be present as issues. Moreover, I aimed to use the longitudinal data to its full potential to look at people's experience over time and look at how issues changed or endured, which Salander's study does not appear to do, focusing instead on the period of time after primary treatment has ended. A lot of the qualitative work exploring the lived experience of glioma has been done in Sweden. Carrying out similar studies in the UK will allow for any cultural differences to be explored.

2.4.3 Psychological issues

A large volume of research illuminates psychological dimensions of illness experience. A selection highlights key issues in order to build a picture of the complexity of adjusting to a serious diagnosis such as glioma.

2.4.3.1 Distress

There are very few articles reporting directly on distress in brain tumour patients although it is a 'by-product' of many psychosocial articles. Distress is a multi-faceted

concept encompassing upset of one's emotional state, a feeling of grief and loss, for example loss of function; quality of life; relationships; independence and self as well as dealing with symptoms and uncertainty about the future (Keir et al., 2008a). This section focused on articles using the specific term distress (although it is ingrained in a number of different concepts reported elsewhere) to explore its potential place in the current study.

Seventy-five patients with a primary brain tumour (aged 24-70 years) were screened for distress using the NCCN Distress Thermometer (DT) (Keir et al., 2008a), a tool that has been evaluated throughout the world e.g. (Akizuki et al., 2003, Hoffman et al., 2004, Gessler et al., 2008). The majority of patients (84%) had a diagnosis of a high-grade tumour and the median time since diagnosis for all participants was 1.8 years. 48% reported low levels of distress, 31% moderate and 21% high levels of distress (based on a cut-off score of 4). Distress was most commonly associated with *emotional* sources (worry, sadness and depression), followed by physical concerns and a high number of overall concerns, with females and those recently diagnosed reporting higher distress than males. Distress was higher than previously reported and higher than people with other cancer diagnoses. Distress was also enduring over time in brain tumour patients (Keir et al., 2008b), and in cancer patients and their relatives (Rabin et al., 2007). Use of the DT has also been evaluated in relatives of cancer patients (Zwahlen et al., 2008). Keir's study provides a useful overview of distress in brain tumour patients. While using a brief tool such as the DT is useful when screening a large number of patients, it lacks the depth of insight to be gained from in-depth qualitative interviews, which would give a better idea of the complexity and scope of the concerns identified.

Ryan *et al* present a synthesis of the issues on detecting and managing psychological distress in cancer patients (Ryan et al., 2005). Factors influencing the increased discussion of patient distress include patients' attitudes and beliefs; educational level

and empowered communication style; physical symptoms overshadowing depressive symptoms; patients normalising symptoms; skills at picking up emotional and non-verbal cues; active listening; and clinicians' attributes such as competence and perceptions of their role. The authors have not provided recommendations on ways in which distress should be managed in cancer patients as they set out in their aims. The review does, however, suggest ways in which services for cancer patients can develop more of a focus on psychosocial care and address their potentially unmet supportive care needs, which has emerged as significant in the present study.

Kelly and colleagues in Canada have examined various clinical tools for detecting and managing distress in people nearing the end of their lives (Kelly *et al.*, 2006). Kelly *et al.* pointed out that while many people will experience fear, sadness and grief as normal responses to their illness, others will go on to develop clinically significant conditions. However, they reported that psychological distress in palliative care often goes unreported and untreated. They agree with Ryan *et al.* (Ryan *et al.*, 2005) that the recognition and treatment of distress in order to preserve patient well-being is crucial, and value tools such as the NCCN Distress Thermometer and Steinhauser's single-item tool for spiritual distress (Steinhauser *et al.*, 2006b) among a number of other tools evaluated. The authors urge caution when choosing a tool due to the number of different conditions measured such as depression, anxiety and delirium. Kelly *et al.* concede that qualitative methods are of 'utmost importance' in understanding psychological distress (Kelly *et al.*, 2006), which I have adopted to understand the different dimensions of the illness experience and sources of distress.

Sherwood *et al.* reported on predictors of distress in caregivers of persons with a primary malignant brain tumour, specifically, the impact that the patients' symptoms and functional status have on the carers' emotional state (Sherwood *et al.*, 2006). Demands placed upon the carer such as assistance with activities of daily living and

dealing with cognitive and neuropsychiatric symptoms were associated with increased caregiver distress and depressive symptoms, and increased support was called for to mitigate this. This quantitative study has been complimented by a more in-depth qualitative study (Sherwood et al., 2004a) and Sherwood's exploration of carers' concerns have been discussed in more detail later in this chapter.

2.4.3.2 Coping

The concept of coping was implicit throughout the literature. Salander's work has looked at coping and these articles have been discussed throughout a number of sections in this chapter. There are few other studies that have explicitly studied coping in brain tumour patients, although there is a vast literature beyond the disease⁴. A small

⁴ There is a large historical literature in psychology looking at cognitive models of coping cited by Sand et al including Lazarus and Folkman's stress response model LAZARUS, R. S. & FOLKMAN, S. (1984) *Stress, appraisal and coping*, New York, Springer Publishing Company, Inc., Rotter's theory of locus of control ROTTER, J. B. (1966) Generalised expectancies for internal versus external control of reinforcement. *Psychological Monograph*, 80, 1-26., Kobasa's theory of hardiness KOBASA, S. (1979) Stressful life events, personality and health: an introduction to hardiness. *Journal of Personal and Social Psychology*, 37, 1-11., Janoff-Bulman's assumptive worlds JANOFF-BULMAN, R. (1992) *Shattered assumptions: towards a new psychology of trauma*, New York, The Free Press., Seligman's theory of learned optimism SELIGMAN, M. E. P. (1991) *Learned optimism*, New York, Knopf., Taylor's cognitive adaptation TAYLOR, S. E. (1983) Adjustment to threatening events. A theory of cognitive adaptation. *American Psychologist*, 38, 1161-1173. and Rutter's concept of resilience RUTTER, M. (1985) Resilience in the face of adversity. *British Journal of Psychiatry*, 147, 598-611.. More recently, Brennan has discussed adjustment to cancer not as coping but as personal transition BRENNAN, J. (2001) Adjustment to cancer - coping or personal transition? . *Psycho-oncology*, 10, 1-18.. Discussion of these theories extends beyond the scope of this thesis (although will be returned to in chapter 11) but it is worth mentioning that a lot of the research in coping has been built on this literature.

selection of papers illustrating the concept of coping have been included in this section to explore and illuminate this dimension of living with glioma to inform this study.

Amato provides a discursive overview of coping with malignant glioma (Amato, 1991). Good communication and information provision and building good relationships between doctors and patients are emphasised to promote successful coping. Amato argues that denial is a useful strategy and professionals should not dispel that, drawing on a paternalistic model of patient care. Research elsewhere suggests patients were more likely to hope for a miracle than carers (Strang and Strang, 2001). The concepts Amato introduces here such as patient autonomy and decision-making as well as use of denial have been subsequently questioned and reframed, positioning the patient not as a passive recipient of care but someone actively using cognitive processes to cope with their illness (Salander et al., 1996, Brennan, 2001). Amato recommends multi-disciplinary working; honest and clear information; patient and caregiver support groups; and staff support.

Strang and Strang have looked at coping strategies in their study with 22 brain tumour patients and 16 carers, identifying three components: comprehensibility, manageability and meaningfulness (Strang and Strang, 2001). Comprehensibility and meaningfulness are discussed in section 2.4.7 in relation to spiritual and existential issues.

Manageability relates to the behavioural component of coping. In order to cope with their diagnosis, people used their own inner resources – strength, hope, positive thinking, distraction (e.g. work, information-seeking), and confidence. Techniques such as distancing, rationalisation, distraction, control, humour and repression were also used. Family, friends and professionals were also integral support for patients and carers.

As part of a larger study, Adelbratt and Strang have reported on coping strategies used to deal with death anxiety in 20 brain tumour patients and 15 spouses (Adelbratt and Strang, 2000). Strategies included use of paraphrasing, irony and distraction; positive thinking; distancing; repression; minimising; bargaining; and emotional isolation. Sand and colleagues also looked at coping in the face of impending death in 20 Swedish people with a palliative cancer diagnosis (Sand et al., 2009). People found it easier to cope when they were physically well, and less so when plagued with troublesome symptoms such as pain, fatigue and nausea. Coping strategies used included personal strength of character; perseverance; a sense of humour; language to describe the illness; magical thinking; and capacity to avoid dark thoughts. 'Togetherness' with friends and family as well as interactions with animals, nature and a 'greater force' provided a means of coping. The ability to join in with life gave a sense of purpose. Hope and reflection on one's place in the world and contribution were also significant. Sand *et al* theorise that people swing on a pendulum between the extremes of life and death, coping and not coping, fulfilment and despair (Sand et al., 2009), suggesting that mood is dynamic and unstable and professional support needs to be sensitive to its role in coping.

Edvardsson and Ahlstrom qualitatively explored coping in 39 persons (27 male, 12 female; mean age 46 years) with a low-grade glioma (Edvardsson and Ahlstrom, 2005). The most frequently cited illness-related problems related to physical and psychological function and communication. Social and environmental concerns were also reported such as financial and employment issues or social isolation. Coping strategies identified were: searching for a solution; refraining from and avoiding things; laughing and joking; caring about self; re-evaluating; giving and seeking information and help; expressing emotions and thoughts; comparing; struggling; maintaining hope; accepting; seeking social affinity; and anticipating. Gustafsson *et al* report on the 'ways of coping' questionnaire results from this group of patients (Gustafsson et al., 2006).

The most dominant coping strategies used were emotion-focused, including positive reappraisal, followed by social support, distancing, self-controlling and escape-avoidance. Problem-focused coping strategies such as planful problem-solving, confrontive coping and accepting responsibility were less common. Escape-avoidance coping was associated with higher levels of emotional distress. These authors have demonstrated vast variation in concerns and illness-related problems as well as the ways in which people deal with their illness, often engaging several different strategies at once.

Salander and Windahl have examined the definition and use of denial, disavowal and avoidance in coping with a brain tumour diagnosis (Salander and Windahl, 1999). Denial was traditionally conceived of in Freudian psychoanalytic theory as a primitive sub-conscious defence mechanism to protect one's psychological well-being. The authors suggest that the notion of 'denial' is misleading and overused in coping research and defer to Freud's lesser used concept of disavowal. They argued that the cancer patient does not necessarily deny their situation, but engages in disavowal, a process by which they 'evade the truth by means of distortion, rationalisation and misinterpretation' [1999: P269]. Disavowal, then, is another cognitive manoeuvre oncology patients may engage to deal with the mental strain of their diagnosis. Salander and Windahl argued for more discerning use of the terminology where the subtle differences in meaning will have a subsequent effect on the way coping is understood. Salander's research provides a rare insight into the psychological coping of brain tumour patients, and in the current study I will add an exploration of experiential coping from the *patient and relative perspective*.

2.4.3.3 Hope

Fostering and maintaining hope appears to be central to dealing with a brain tumour diagnosis and research into psychosocial issues and coping returns again and again to theories of hope (e.g. Janda et al., 2006, Scheier and Carver, 2001). Maintaining positive thoughts, beliefs, hopes and dreams about one's current and future situation is viewed as a way of coping. Hope also gives a focus on the meaning of life, faith and trust in order to make life worth living (Edvardsson and Ahlstrom, 2005). Hope can be seen as multi-dimensional and not a linear continuum between hope and hopelessness (Nekolaichuk et al., 1999). It was important to examine the use of hope in brain tumour patients specifically in order to inform health professionals' approach to understanding and sustaining it. A selection of articles exploring hope and its implications for communication in oncology are thus reported.

Salander *et al* have explored how brain tumour patients use cognitive reframing to create protection and hope to assist coping (Salander et al., 1996). Repeated interviews were used to explore how 19 high-grade glioma patients positively re-evaluate their situation and maintained hope despite their poor prognosis in the early phase following diagnosis. Patients used 'cognitive manoeuvres' to create hope from four sources: feeling physically well; focusing on something positive such as treatment or favourable comparison with others; adaptation of cognitive schema or ways of thinking about one's circumstances (e.g. changing outlook on life, wishful thinking, avoiding harmful thoughts); and the handling of information (e.g. viewing it in a more positive light, selective attention to reassuring information). Patients who coped successfully were more likely to have had full surgical resection of their tumour and good postoperative health, drawing on physical health as a source of hope, while half of those not coping had not had surgery. This theory does resonate with some of the

quality of life studies that have found better psychological adjustment and overall quality of life in people with better physical functioning (see section 2.4.6).

Clayton and colleagues have previously explored the balance to be struck between honest communications and fostering hope and adaptive coping (Clayton et al., 2005b). More recently, Clayton *et al* have conducted a systematic review including 27 articles on sustaining hope during conversations about prognosis and end of life issues for terminally ill patients and their families (Clayton et al., 2008). Strategies for sustaining hope include avoidance - where people avoided detailed information or focused on positive information; balancing honesty with optimism; nurturing hope by framing discussions with health professionals positively. Studies involving health professionals revealed reservations about colluding with patients' unrealistic expectations, a key challenge for health professionals (Hagerty et al., 2005). Clayton *et al* make a number of recommendations based on the findings of their review: determine individual preferences; be honest and open without being blunt or providing too much factual information; offer reassurance; emphasise what *can* be done; reassure that treatments are available to control pain and other symptoms; identify areas where control is possible; and recognise the spectrum of different forms of hope; important insights to inform outcomes of the present study.

Leydon *et al* have conducted a qualitative analysis of 28 consultations between consultant oncologists and cancer patients (Leydon, 2008). Techniques identified to promote hope included mitigating distressing news by focusing on relatively better information and ordering the delivery of information so that the 'take home message' was optimistic. Positive consultations also promoted an optimistic environment and relationship between doctors and patients. This study examines consultations later in patients' trajectories and it would be valuable to examine consultations at diagnosis. Moreover, the consultants in this study had several years of experience and could differ

from less experienced practitioners. An evaluation of patients' views about consultations and whether their own expectations are being met would also be valuable. Finally, this study was conducted with participants that had a chance of a cure and could vary from those with a terminal diagnosis.

Wiles *et al* synthesised qualitative research papers exploring hope (Wiles et al., 2008). The authors conceptualised two forms of hope, not otherwise distinguished in the literature. 'Particularised' hope refers to a wish, want or expectation of a particular outcome and knowledge that the outcome is either likely (expectation) or unlikely (desire). 'Generalised' hope is defined as a state that gives life meaning and protects against despair. Seven papers were included in the final review, covering a range of patient groups. Hope for recovery was identified as a desired outcome (want) rather than an expected one. Wiles *et al* caution whether it is possible to detect realistic versus unrealistic hope when the person might actually be expressing a want rather than an expectation, such that individual definitions and functions of hope should be explored. Positive thinking, religious faith, faith in the medical profession and technological advances, personal control, and having a strong will were all reported as ways of keeping hope alive. The changing nature of hope was discussed in five of the seven papers reviewed. One distinctive shift is from a concrete hope for recovery in the early or crisis stages of the illness to a more realistic hope as people gain knowledge and have time to adapt, which has been identified in spinal cord patients in another recent study (Lohne, 2008). Wiles *et al*'s review makes an important distinction between different types of and orientations to hope, possibly as an artefact of the different researchers but it could also be related to different illnesses.

2.4.3.4 Clinical depression/ anxiety

There are a number of articles in the literature looking at depression and anxiety in people with brain tumours. Depression in glioma is not a primary focus of this thesis and is currently being investigated in patients attending the study hospital⁵. A selection of articles identified with a number of different approaches to measuring and understanding depression are therefore summarised in Appendix Two to inform the holistic picture of the experience of glioma.

2.4.4 Information and communication

Information and communication issues have been exhaustively researched for patients with cancer but there remains a dearth of articles focused solely on brain tumour patients' needs, despite being selected as a priority issue for improving care (NICE, 2006a). This topic was considered an important dimension of the experience of glioma and thus warranted close attention in this review. This section therefore reports on issues for brain tumour patients; what patients and their families want to know; and interventions and service developments to improve information and communication.

2.4.4.1 Information and communication for brain tumour patients

Davies and Higginson have reviewed literature on communication, information and support for glioma patients, identifying studies on knowledge of diagnosis and prognosis; information needs; breaking bad news consultations; effective communication; perceived support needs; role of the specialist nurse; and communications training for health professionals (Davies and Higginson, 2003). 16

⁵ Alistair Rooney is currently looking at depression in glioma patients at the study hospital.

papers reporting 12 studies were synthesised. The authors argue that, with varying levels of awareness of prognosis, information should be tailored to the needs of the individual patient as well as relatives, whose behaviour and levels of distress seem to vary from those of the patient. Elsewhere in the literature, relatives were found to have greater information needs than patients (Durity et al., 2000), who sometimes felt knowing was better than not knowing (Wyness et al., 2002), adding to the debate summarised in Davies and Higginson's review over whether information contributes to distress (Anderson et al., 1999, Davies et al., 1996b). In addition, maintaining hope was found to be crucial for patients and specialist nurses provided an important role in providing information and support. Sample biases, limited settings and lack of description of methods used were a concern for the reviewers. Nevertheless, a number of areas for improvement were derived: tailoring information to patients and their relatives; increased consistency of information; better communication between health professionals; and a greater understanding of the preferred and most effective methods of obtaining information for patients and their relatives.

Janda *et al* explored the information and communication needs of brain tumour patients in an Australian study involving focus groups and telephone interviews (Janda et al., 2006). Patients and carers reported an urgent unmet need for written and verbal information around the time of diagnosis. Respondents wanted a designated contact member of their clinical team (similar to the UK specialist nurse) as a source of information, support, and improved care. Carers requested more information on dealing with practical issues and crises. Finally, carers in particular were in favour of a source of information, via computer or telephone, against which to verify information and decision-making. There was caution that too much information could be damaging, as has been highlighted in the information literature more generally. Reservations when interpreting Janda *et al*'s findings have been discussed in section 2.4.5 on supportive care issues.

Two studies have shown acceptability of a UK nurse-led telephone follow-up service for brain tumour patients as a source of information, advice and support (Sardell et al., 2000, Curren, 2001). Advice about symptoms, treatments and side effects of medications as well as emotional support were helpful for patients and particularly carers.

2.4.4.2 Information and communication for patients with a general cancer diagnosis

A large literature looking at the issues for cancer patients more generally can also inform practice for glioma and other brain tumour patients. These detailed and in-depth findings highlight the complexity of information needs: the type of information required, personal differences and the timing of delivering it - thus building a picture of how best to improve information provision and the current study situates the views of glioma patients within this.

Butow *et al* emphasised the importance of information and suggested that a person's information needs and coping style may change when they are ill (Butow et al., 1997). In their study, Butow *et al* looked at how stable a group of 80 Australian cancer patients' (20 male, 60 female; aged 18-87) information, involvement and support preferences were before and after a consultation (10 new patient consultations, 66 routine follow-ups and 24 given news of significant change) and in 40 patients followed up three to six months later. In the pre-consultation period, 85% wanted a large volume of information about their illness whereas 15% wanted minimal detail. 36.3% of participants wanted a collaborative role, 22.6% an active role and 41.3% a passive role in decision-making about their care. The highest ranking support needs were: more feedback on what is happening with their cancer (97%); information about the future (88%) and more information about their illness (91%). After the first consultation, patients' needs shifted from information and involvement to emotional support, with a

need for reassurance and hope (59%); assurance they would be looked after (63%); and to talk about concerns and anxieties (59%). By the time of the next consultation patients' need for information had increased again and their desire for support was sustained. There was a clear preference for less information and involvement after the consultation with a doctor. Females sought more detailed information than males and patients consulting for the first time were more likely to want greater involvement in decision-making than those consulting about a significant change in their illness. It seems information and involvement preferences do shift when patients come under threat, with patients preferring to defer judgement to the doctor. However, elsewhere, this research team showed that use of a 'question prompt sheet' in consultations led to increased questions about prognosis (Butow et al., 1994), decreased anxiety and shorter consultations if the sheet was used by professionals (Brown et al., 2001). Therefore, capacity for involvement appears to relate to support, preparation and the communication skills of doctors; concepts that have been addressed in chapter 11.

Voogt *et al* have investigated 128 patients' (62 male, 66 female, mean age 63.6) views on the sufficiency of information received within two months of receiving a diagnosis of an incurable cancer (breast, lung, colon, ovary or prostate) (Voogt et al., 2005). Patients reported feeling well informed about: treatment options and side effects (96%); physical symptoms (80%); helpful devices (67%); organisations that provide help (68%); and diet (56%). Patients were less informed about: cause of their cancer (35%); psychosocial care (29%); impact of cancer on sexuality (28%); care settings (22%); euthanasia (17%); alternative medicine (14%) and complementary care (7%).

However, recall does not necessarily correlate with understanding. Oncology nurses in Voogt's study were considered to provide the best quality information (88%) compared with 80% of clinical specialists, 78% of non-specialist nurses and 63% of general practitioners (Voogt et al., 2005). Overall, 39% of patients reported a desire for further

information on the topics listed above as well as more information on treatment options and side effects. 19% of patients required more written information. Patients with a higher level of education, longer disease duration, patients with ovarian cancer and those with a heightened level of anxiety all expressed a greater need for more information. Lung cancer patients rarely expressed a need for more information and depression was not related to information need. Varying findings reported in this section across different cancer types and cultures demonstrate the complexity of information needs and the need for continued research.

Pollock *et al* have recently provided some qualitative evidence of 27 lung, head and neck cancer patients' and their relatives' views of information delivery over a period of one year following diagnosis (Pollock et al., 2008). Overall, patients did not seek as much information as their carers. Participants focused on verbal information and viewed written information, provided it was consistent, as supportive rather than a direct source of knowledge. Participants felt unable to deal with large amounts of complex information but appreciated their doctor giving direct, honest and clear information at diagnosis and this helped to establish trust in their relationship. Patients also reported a preference for tailored personal information, a common finding in the wider literature (Rogers et al., 2009). Information was not reported as a high priority for patients during the time they were being referred and investigated due to the speed of events. This appears at odds with some of the literature presented in this review and elsewhere in the literature e.g. (Jenkins et al., 2001), although shock of diagnosis could affect people's ability to retain information, suggesting further investigation of this crucial period is needed. Participants did not wish to become involved in the decision-making process about their disease, instead having faith in their consultant's expertise to advocate for them. This reflects suggestion in the literature that critically ill patients may take on a more passive role (Butow et al., 1997, Maguire, 1999, Rier, 2000).

However, it is likely that Pollock *et al*'s findings show the complexity of what involvement means, and people may want to participate in discussion without making final decisions (Fallowfield, 2001, Fallowfield et al., 2002). Also, respondents valued being given information on procedures and treatments without necessarily making decisions and so were involved in this way (Pollock et al., 2008). Use of decision aids can empower patients and increases participation (O'Connor et al., 2008). People sought mainly positive information to suppress uncertainty and anxiety and promote hope, as evident elsewhere (Leydon, 2008), emphasising that *type* of information is important. Participants also wanted more information about what to expect once their treatment was finished and information that was specific to them. There were mixed views about prognosis: some patients wanted a precise figure on how long they were expected to live, while others faced a dilemma and preferred to work on a 'need to know' basis. Non-verbal and incidental communications from doctors were also powerful cues for patients and closely attended to.

Grbich *et al* have looked at the information needs of caregivers of terminal cancer patients over an 18-month period, including after bereavement, combining longitudinal case studies, focus groups and questionnaires to form a large dataset (Grbich et al., 2000). Caregivers reported a lack of information, particularly around diagnosis. Key areas of information need included: understanding the disease process; understanding treatment, medication and side effects; choice regarding treatment options; and what to expect in the future stages of the illness. A minority of caregivers wanted to shield the patient from the news of a terminal diagnosis. These findings again echo those of Butow *et al* with regard to the cancer patient themselves (Butow et al., 1994, Butow et al., 1997) and elsewhere in the literature e.g.(Meredith et al., 1996). There was variation in the literature about the level of information patients and carers wanted about the illness and how this relates to distress. The precise methods used by Grbich *et al*, particularly the analysis of longitudinal data, are not made clear and therefore it is not

possible to situate the views in a timescale. It is likely that needs changed over time but this issue was not clear. The complexity of information needs over time has been explored more closely in this thesis.

2.4.4.3 Breaking bad news

A lack of papers relating to breaking bad news of diagnosis and prognosis to high-grade glioma patients was recognised as an area for future research and interventions (Catt et al., 2008). This crucial period is recognised as important in shaping adjustment and patients' future interaction with, and experience of, health services (Fallowfield, 1993, Friedrichsen et al., 2000, Mager and Andrykowski, 2002, Leydon et al., 2003). Thus, a sample of general articles give an overview of the relevant issues to inform this study.

Parker *et al* sought to provide an evidence base for future development of protocols on breaking bad news in their study of 351 US cancer patients (60% female, 40% male; aged 28-80) at various times since diagnosis (Parker et al., 2001). Parker *et al* found that while supportive aspects of communication are valued by patients at the time they are receiving bad news, content (what is said) and assurances of their doctor's competence and expertise are most reassuring. Factors such as environment when being told the news took lowest priority but did feature on patients' agendas. There was a significant correlation between coping style - being a 'monitor' (proactive) as opposed to a 'blunter' (avoidant) as measured by the Miller Behavioural Style Scale (Miller, 1987) - and a desire for more detailed information. Females were more likely than men to value the content of the information given and the supportive aspects of the communication. Those with a higher level of education valued content and context in which the news was told, as did younger patients, a finding echoed by Voogt *et al* (Voogt et al., 2005).

This study would benefit from a greater insight into how patients' preferences for communication of bad news change over time and at key transitions.

Salander has reported on people's perspectives on hearing bad news of a cancer diagnosis in a study of 138 (45 men and 93 women; various diagnoses) written narratives of 'hearing the news' (Salander, 2002). Many respondents gave detailed, intimate accounts, particularly when their experience had been particularly difficult, as reported elsewhere (Leavitt et al., 1996). A minority of participants gave very short, factual accounts of their diagnosis. People talked about their diagnosis as a *process* and focused not on their interaction with medical services but placed experiences in a wider context. Salander identified three broad categories: experiences of the setting (both physical setting and atmosphere created by professionals, valuing reassurance and empathy); experience of care (regular and positive contact; continuity of timely care; time, attention and kindness to process information); and experiences of disease information (being informed; being prepared; sensitivity and timely delivery; empathy and support; honest and clear information; being able to plan and restore order; lack of information led to anxiety and distress). Routines provided comfort and expectation, giving way to hope (Salander, 2000, Salander et al., 1996). Salander emphasises building up good quality relationships based on a two-way interaction. Importantly, Salander questions whether making patients fully informed and central to the decision-making process is what motivates people. Instead, he theorises that information about treatment plays the role of creating hope and facilitating coping, with important implications for the careful communication of bad news (Friedrichsen et al., 2000).

In-depth prospective data from this study from the time of diagnosis can add to what is known about this time in the patient's illness journey with implications for improving the implementation of guidelines, training and structures to address communication issues.

2.4.4.4 Information and communication at the end of life

Provision of sensitively communicated information becomes even more crucial at the end of life when discussions centre on highly emotive and potentially distressing topics such as prognosis, lack of treatment options, death, dying and end of life care. Patients' and carers' information needs may be different at this time compared to other stages of the illness and this warrants close attention. The debate continues on what type of information should be given and to whom, and how it should be delivered in a timely fashion (Hurny, 2002). A selection of two papers looking at advanced cancer using different methodology and approaches to the topic have been included in this section of the review to give an insight into how it may be for glioma patients at this time.

Wong *et al* in Canada have done an information needs assessment for patients with advanced cancer and their carers, in order to plan an intervention to educate patients at this stage in their illness (Wong et al., 2002). 144 participants (71 patients and 73 carers) were surveyed to determine their informational needs, the medium through which these are best delivered and their interest in an educational event to improve their knowledge of end of life issues. Patient and carer information needs included: management for pain control (78%); management for weakness and fatigue (62%); and home care services (52%). Respondents were also interested to understand more about the nature of cancer, its causes and how to communicate with loved ones. Other topics that were of interest to less than half of respondents included such things as shortness of breath; depression; weight and appetite loss; home palliative care programs; and pain clinics. The items rated of lowest interest included clinical trials, palliative radiotherapy clinics, advanced directives and support groups. Overall, carers had a higher level of interest in information and in different types of information than the patients themselves. Information on symptom control was of more interest to patients. Carers, on the other hand, were interested in understanding cancer and managing their

loved one's illness. Different methods of information delivery preferred by all respondents in this study included one-to-one (66%); pamphlets (50%); seminars (30%); and books (30%). Retrieving information from the internet was the least popular source (17%). Participants had mixed feelings about attending an educational event and resisted mainly due to practical reasons. It is important to note that the views of patients at the end of life *not* receiving palliative treatment were not taken into account in this study; a group that potentially have more significant unmet need. A more in-depth exploration of views would complement this questionnaire study.

Clayton *et al* have examined communication with terminally ill cancer patients based on focus groups and telephone interviews with 19 patients, 24 carers and 22 professionals working in palliative care (Clayton et al., 2005a). Patients wished to go over treatment options with a palliative care specialist rather than the oncologist providing the treatment, a sentiment echoed by staff. However, only one health professional voluntarily mentioned end of life treatment planning. Patients sought less detail in information about symptoms at the end of life than carers. Patients wanted to ensure they would not be in pain, to die with dignity and with loved ones surrounding them. Carers sought more practical information and skills to prepare them for looking after their loved one, although they were cautious of being overwhelmed with information. Professionals sought to convey a message of gradual bodily decline and comfort at the end of life. Patients did not raise issues on place of death but carers wanted to discuss this topic and doctors felt these discussions were important early on, acknowledging the role of family members. Existential issues were not raised by patients and carers and professionals did not feel it was their role to do so unless prompted. Palliative care specialists were very keen to discuss the process of dying such as exploring fears and dispelling myths, and felt that despite fears and reservations, patients and carers do benefit from such discussions.

The present study can contribute to what is known about patients' views on end of life discussions so that communication can be configured accordingly. It is unclear whether existential issues had low priority for people or whether they were inhibited from talking about it, and the present study will contribute to this discussion. In-depth interviews with health professionals working in non-specialist palliative care settings also provide a valuable supplement to this subject area.

2.4.4.5 Improving information and communication in oncology

There has been a concerted effort to improve communication skills among health professionals by providing guidelines (Girgis and Sanson-Fisher, 1998) and training programmes (Fallowfield et al., 1998), although a lack of adequate training remains (Fallowfield, 2005); a potential source of continued communication breakdown (Hurny, 2000). Although difficult to evaluate, a review of communications training programmes has shown them to improve skills, particularly when a behavioural component is built into the programme (Gysels et al., 2005). However, communication skills are not part of standardised practice and the long term effects of such practice have not been evaluated (Hurny, 2002). Fallowfield agrees that while much research and discussion is produced on the matter, little is known about the implementation and sustenance of guidelines and interventions (Fallowfield, 2005). Moreover, hospital culture and historical roles are difficult to break down (Kinnersley et al., 2008). The evidence presented in the previous sections of this review shows a lack of satisfaction with communication and information and certainly scope for further progress.

Kinnersley *et al* have systematically reviewed 33 studies evaluating the impact of interventions to increase information gathered and questions asked in consultations with health professionals (Kinnersley et al., 2008). A meta-analysis of the findings showed small but significant increases in number of questions asked and patients'

satisfaction, and non-significant increases in levels of anxiety before and after the consultation, patients' knowledge, and the length of the consultation. Not all of the studies included in Kinnersley *et al*'s review were based in oncology settings and therefore the results must be interpreted with caution when applied to patients with cancer. Also, a range of different settings and methods used makes it difficult to synthesise the evidence.

Information needs among glioma patients, and in cancer patients in general, appear to be complex and neuro-oncology suffers from a lack of controlled studies to evaluate information delivery and communications training. Moreover, there are a limited number of in-depth qualitative studies exploring glioma patients' views and perceived information and communication needs and in particular how these change over time, which are addressed in this thesis.

2.4.5 Supportive care needs

Professional supportive care has undergone considerable conceptual development in recent years. The traditional definition of supportive care focused on side effects of treatment and making the patient comfortable (Cancer Web, 1998), but the term has since come to have a more holistic meaning born from patient-centred palliative care and encompassing psychosocial, emotional, informational, practical and spiritual needs e.g. (Piggot et al., 2009). In this section of the review I present a range of relevant papers exploring the supportive care needs of brain tumour and other cancer patients.

2.4.5.1 Supportive care in neuro-oncology

Catt *et al* have recently conducted a literature review of psychosocial and supportive care needs for patients with high-grade glioma (Catt et al., 2008), covering the publications since Davies and Hopkins' original work (Davies and Hopkins, 1997b). The need to balance out the wealth of randomised controlled trials with more attention to psychosocial, existential and supportive care is emphasised. Distinctive problems such as cognitive and neuropsychological deficits and the adverse effect of fatigue on quality of life are highlighted. The role of nurse specialist support is also indicated as widely appreciated in neuro-oncology. Finally, Catt *et al* have found little in the literature on the palliative care needs of glioma patients. The authors pointed out that while research involving glioma patients has increased in the last ten years, it is still beset by problems of access, recruitment and attrition and specific areas such as interventions for cognitive deficits have little known about them, calling for a better understanding of the needs of this patient group, a problem I have attempted to address.

Janda *et al* have recently explored the supportive care needs of glioma patients in Australia (Janda et al., 2006, Janda et al., 2008). The number of supportive care needs listed by brain tumour patients are distinctive and exceed those found in studies of other cancer patients, comparing living with a brain tumour to living with metastatic disease of other cancer types (Janda et al., 2008). A framework analysis of data from focus groups and telephone interviews involved 18 patients (seven male, 11 female; aged 27-79 years) and 18 carers (4 male, 14 female; aged 30-83 years) (Janda et al., 2006). A number of practical support needs were reported including help when dealing with financial issues such as filling out forms. Janda *et al* found that patients' needs diversified after the preliminary phase of the illness and treatment, dependent on whether or not patients were able to return to their previous level of function and

activity. Patients requested professional support to negotiate their return to work. Carers of loved ones with poor functional ability were concerned with how best to care for them, and sought skill and support. Patients did not want to be a burden and emphasised the need for respite services. Patients and carers voiced social isolation and requested assistance in fostering and maintaining hope. They praised the support gained from palliative care services and these agencies were considered much better equipped in meeting their needs. Recommendations included: assigning a dedicated case manager; proactive dissemination of information, educational materials and psychosocial support; objective assessment of neuropsychological functioning; facilitating access to welfare payments; and preparation for deterioration and end of life treatment decisions. However, patients recruited were already receiving specialist supportive care from a brain tumour support service, of which no UK equivalent exists. Therefore, it is a point of interest to explore the supportive care needs of brain tumour patients in this country as I have done. Furthermore, Janda *et al* included patients with non-malignant disease, for which the implications for prognosis and supportive care differ, warranting separate attention.

Curren has explored the place of a nurse specialist telephone service to provide for unmet support needs (Curren, 2001). Nurse specialists have similarly been identified as a valuable resource elsewhere (Spetz et al., 2005). An audit evaluation of the service found it to be easy to access; promote communication and continuity of care; and a good source of information, practical advice and emotional support, particularly for carers. In addition, such a service could be cost effective as a result of more timely reduction of steroids and reduced general practitioner contact. Problems included potential for misunderstanding over the phone and marginalisation of patients with diminished cognitive or speech function. A satisfaction questionnaire of a similar service for patients with high-grade glioma showed acceptance and high satisfaction with the service (95% were confident in the nurse although 13 people would have

preferred joint doctor and nurse follow-up) (Sardell et al., 2000). However, as with Curren's study, patients with cognitive or speech deficits were excluded and in this study carers were also excluded. Finally, there was no control group with which to compare satisfaction.

Further research is signalled in this area to evaluate effective interventions to provide support to glioma patients and their carers targeted at various transitions in the illness journey (Davies and Higginson, 2003), which this study can, in part, address.

2.4.5.2 Supportive care for all cancer patients and carers

Meeting the supportive care needs of cancer patients was put firmly on the NHS agenda first by the Calman-Hine report (Expert Advisory Group on Cancer, 1995) followed by the NHS Cancer Plan (Department of Health, 2000). The government set out to provide better communications and support training to staff and expand palliative care services to provide optimum informational and psychological support to patients. Nearly ten years on, the supportive care agenda remains a priority but has yet to reach an acceptable level. Research papers presented in this section show that unmet needs remain and more work is needed to fully understand how best to provide for them, an objective of the present study.

Challenges to the cancer and palliative care nurse specialist role have been identified (Willard and Luker, 2005). Nurses reported, in 29 interviews, that organisational and resource constraints; culturally ingrained ways of working; and lack of timely referrals to palliative care services inhibited their ability to provide comprehensive support. This paper provides a useful insight into one professional role involved in the provision of supportive care. Understanding the systems for provision of care is important, but

without the patient's perspective it is not possible to fully develop services to address unmet needs (Soothill et al., 2001a).

Soothill *et al* explored unmet support needs of cancer patients in survey of 295 patients with mixed diagnoses combined with 47 qualitative interviews at four key transition phases: diagnosis, end of first treatment, first recurrence and those shifting into palliative care (Soothill et al., 2001a). The study was reportedly subject to selection bias due to consultant gatekeeping and low response rate. Overall, there was a relatively low level of significant unmet needs (62%) but a small proportion of the respondents had a large number of unmet needs (4.4% had more than 10 unmet needs). The results show that top-rated needs are mostly being met but other (still important) needs, further down their list of priorities, are not. Core needs reported were: having confidence in health professionals; easy access; and time devoted to discussing their concerns. The remainder of needs were more diverse and reliant on patients' specific social circumstances (e.g. help with childcare), and should be addressed case by case. Younger patients, those with poorer health status, without a car, not having a faith, not being able to talk to their carer, illness interfering with social activities and financial difficulties were all associated with having unmet needs. Needs were not greater at any particular time. On the whole, patients were satisfied with their medical care but did suffer from unmet emotional and supportive care needs, particularly when they had markers of poor socio-economic status and social capital. Soothill *et al* argued that multi-disciplinary professionals should work together to provide for patients' psychosocial needs in addition to their medical needs.

A similar survey of 888 cancer patients attending nine Australian cancer treatment centres was conducted three months or more after diagnosis (Sanson-Fisher et al., 2000). The top ten unmet needs in the psychological, health system and information and physical and daily living domains of the survey were fears about the cancer spreading;

fears of cancer returning; concerns about the worries of those closest to you; information about things to help yourself get well; lack of energy/ tiredness; not being able to do the things you used to do; uncertainty about the future; to be informed about remission; to be informed about test results as soon as possible; and concerns about the ability of carers. Respondents whose cancer was not in remission; younger patients; women and those in particular geographical areas had the highest level of psychological need. Those not in remission; younger patients; and those who had received immunotherapy compared with those receiving other treatments had the highest health system and information needs. Finally, not being in remission; being female; the date of last hospital admission and the location of the cancer centre were predictive of some level of physical and daily living needs. Similar to Soothill *et al* above, psychological needs - such as dealing with uncertainty, sadness, anger and others' feelings - were greatest. Further research in this area will provide a greater insight into what needs to be done to improve satisfaction and outcomes. However, other studies have shown that satisfaction is not always associated with subsequent psychological outcomes, suggesting more work to explore this relationship (Litofsky *et al.*, 2004, Mager and Andrykowski, 2002).

Piggot *et al* have developed a standard screening tool, the Supportive Needs Screening Tool (SNST), to provide an accurate and simple way of ascertaining cancer patients' supportive care needs and facilitating appropriate referrals (Piggot *et al.*, 2009). The tool was derived from 340 questions from 20 existing research and clinical tools and covered five domains: physical, social, psychological, informational and spiritual and were evaluated in a group of 87 cancer patients. Again, social, psychological and informational needs rated high on patients' priorities (97%, 62% and 44% respectively). However, all patients in this study also reported at least one unmet physical need and 30% of patients had spiritual needs. A higher overall level of need was reported compared with Soothill *et al*, although this could reflect Soothill's strict criterion.

Patients were followed-up and referred on where appropriate to nursing, social work, physiotherapy, dietician or occupational therapy, although notably not pastoral care despite the level of spiritual needs. A sub-sample of patients and staff rated the SNST as satisfactory. Issues were raised about the integration of the tool into normal working practice and how to best address the needs identified. In addition, the validity, applicability and acceptability in other oncology settings and phases of illness remain to be seen. This tool closely resembles the NCCN Distress Thermometer with the exception of greater emphasis on informational support, confirming that there is a range of different tools to measure a similar phenomenon.

Howell *et al* evaluated a Canadian nurse-led programme of community-based supportive care involving 700 cancer patients over one year and interviewed health and health-related professionals, managers and service providers (Howell et al., 2008). Nurses were concerned that these patients were not having their supportive care needs met in a timely and appropriate way. Patients and community cancer nurses often wished they had been put in contact with one another earlier in the disease trajectory. Length of time spent varied depending on need, with those struggling to adapt requiring greater input. Community-based supportive care linked with the healthcare system and helped people address the physical and emotional impact of their disease, treatment side effects and problems accessing supportive care in the community. A case note review of 113 patients showed that in 95% of cases nurses did a holistic supportive care assessment. 68% of service providers viewed the specialist oncology nurse as important in the provision of supportive care, although there was some resistance from certain agencies. This programme was successful in meeting patients' needs and making services accessible, timely and continuous with potential to improve patients' physical and psychosocial functioning and global quality of life and should have been introduced sooner in patients' trajectories.

Gaps in information and education form a significant part of patients' and carers' needs in addition to emotional and psychosocial support, which many patients rely on professional services for. The different measures and approaches to capturing unmet supportive needs can be confusing. The range of needs identified at different stages and in different settings is an artefact of the varying methods used, leading to separate studies capturing similar concepts with different terms and language that are difficult to synthesise. The present qualitative study aimed to capture the issues *in the words* of the people going through the experience.

2.4.6 Social network and support

There is evidence in this chapter that good quality relationships and support from friends and family are central to coping with a devastating illness for both the person with the diagnosis and their carers. This section explores this dimension of experience further.

2.4.6.1 Supportive relationships

A heavy reliance on family and friends for support when dealing a brain tumour is indicated, particularly in the early phase of the disease (Janda et al., 2006). Support from family and colleagues were also crucial when attempting to rehabilitate, including returning to work, and impacted on anxiety and depression (Jones et al., 2006). Health and other professionals were also an important source of support e.g. (Burns et al., 2005). Patients and carers in a range of different studies reported anxiety and distress resulting from social isolation, stigmatisation, feeling misunderstood and unable to talk (Courstens et al., 1996, Janda et al., 2006, Jones et al., 2006). Patients with advanced disease and poor functional status also reported lower social support (Courstens et al.,

1996). A complex and changing relationship between social support and survival has also been investigated, with patients with a small number of close confidants appearing to live longer (Burns et al., 2005). Moreover, married individuals were more likely to be depressed and single patients were more anxious than their counterparts (Kaplan and Miner, 2000). However, the latter results should be interpreted with caution due to the small sample size with only eight single participants at one time point.

The role of social and emotional support from friends and family members, health professionals and other people with a cancer diagnosis have been shown to play an important role in reducing distress and helping people to cope with the difficulties of living with cancer. Social support has been explored further in the present study in relation to those living with glioma.

2.4.6.2 Support groups

The perceived value of the support group mechanism appears to vary across individuals. For some, they provide a sense of community, source of information and a safe context to explore one's feelings (Leavitt et al., 1996) while others do not feel they needed this extra layer of support (Grande et al., 2006). A more detailed discussion on support groups can be found in Appendix Three.

2.4.6 Quality of life

Quality of life in patients with brain tumours has received attention of late in the research literature. Like distress, depression and supportive care, a number of different measures and approaches to and definitions of understanding quality of life exist. Historically, there was an emphasis on physical aspects of quality of life (Huang et al.,

2001) and it is only in recent years that other dimensions have been introduced (e.g. (Giovagnoli et al., 1996, Weitzner et al., 1996, Lyons, 1996)). An exhaustive number of other studies were conducted examining a number of different relationships with quality of life such as tumour laterality (Salo et al., 2002); cognitive status (Hahn et al., 2003); quality of life and psychological well-being in long-term survivors of glioblastoma (Schmidinger et al., 2003); and gender differences in depression and quality of life (Mainio et al., 2006a). Quality of life is considered to be disease-specific and so it made sense to focus on the research concerning brain tumour patients (Weitzner and Meyers, 1997).

A disease-specific tool for brain tumour patients was developed to capture physical functioning; relatives and relationships; emotional state; social functioning; the future; ongoing needs; and neurological deficit, to be rated on a Likert scale alongside overall quality of life (Lyons, 1996). The so-called PRESTON profile was designed by the author of the study but no detail about how the topics and questions were decided on was given. 20 patients were asked to fill out the profile and comments were largely positive with all patients rating quality of life average or above. This instrument did not include cognition, which has been shown elsewhere to be an important facet of quality of life (Taphoorn et al., 1994).

Pelletier *et al* examined the relationship between depression, fatigue, emotional distress, existential issues and overall quality of life in 60 brain tumour patients attending a Canadian oncology centre for ongoing care (Pelletier et al., 2002). Results suggested a high level of distress and burden among participants (38% with depressive symptoms). Quality of life was relatively high overall. However, low energy and fatigue were reported in a significant proportion and half reported existential distress. Results showed inter-correlation between symptoms of depression, fatigue, emotional distress and existential concerns except for between fatigue and emotional distress. Longer

survival was associated with increased emotional distress but was not related to depressive symptoms, fatigue or existential concerns. This study did not give an indication of how patients' psychological adjustment and quality of life changed over time nor did it allow for pertinent issues not listed in the battery of instruments used. However, as the authors concluded, it drew attention to important psychosocial issues and flags the need to incorporate these additional needs into service provision.

The relationship between fatigue and quality of life has been investigated in 60 patients (39 male, 21 female; mean age 57) with high-grade glioma (Lovely et al., 1999) as part of a larger study in glioblastoma patients between diagnosis and end of radiotherapy (Lovely, 1996). Fatigue increased over time, associated with poorer overall quality of life and poorer physical, psychological, interpersonal well-being and symptom management. However, these findings were based on a small sample size and excluded patients with a poor performance status.

Brown *et al* have also reported a clear association between fatigue and quality of life as well as increased fatigue being an overall predictor of survival (Brown et al., 2006). Brown and colleagues followed patients up over four months and at one more time point than Lovely *et al's* study. Elsewhere, Brown *et al* have shown that gross total resection of glioma is associated with prolonged life and improved quality of life over a four month period in a study of 98 high-grade glioma patients (Brown et al., 2005). This study provided validation of surgical intervention in high-grade glioma patients but did not give adequate insight into the experience of the patients as they went through diagnosis, treatment and follow-up.

Taphoorn *et al* found no significant impact of radiotherapy in low-grade glioma on quality of life, when compared with patients who underwent surgery and biopsy alone but poorer overall quality of life when compared with a control group (Taphoorn et al.,

1992, Taphoorn et al., 1994). While the authors considered that this has implications for early radiation treatment for low-grade glioma patients, they have not captured the potential long-term late effects of such treatment on these patients. In addition, small sample size precludes any firm conclusions being made.

Fox and Lantz (1998) conducted a qualitative study in order to more fully understand the quality of life of brain tumour patients in their own terms, to redress the lack of research exploring psychosocial and spiritual elements of quality of life (Fox and Lantz, 1998). Twenty-three brain tumour patients and 21 carers were interviewed, identifying the following contingents on quality of life: feelings of isolation; dealing with physical and cognitive symptoms; changing identity; the role of religion; concern for the impact of the disease on the family; and navigating the medical system and the associated communication and information problems.

Stage of disease in glioma and treatment effects also influence quality of life (Giovagnoli et al., 1996, Giovagnoli, 1999, Giovagnoli et al., 2005). Fifty-seven patients (30 male, 27 female; mean age 39.95) with a stable malignant brain tumour after surgery and radiotherapy and 24 patients (11 male, 13 female; mean age 49.29) in a control group of other neurological diseases were studied (Giovagnoli, 1999). Brain tumour patients experiencing stable disease had a comparable level of quality of life to patients in the control group. Quality of life was significantly associated with depression, state anxiety and performance status, with depression the most significant predictor of poor quality of life. Elsewhere, a qualitative study with bereaved carers links good quality of life with low levels of distress, ability to resume activities and good relationships while poor quality of life was related to deteriorating condition and social withdrawal (Davies and Clarke, 2005). In recurrent glioma, better quality of life was associated with lower grade tumours, better functionality, cognition and mood (Giovagnoli et al., 2005). Those closest to initial recurrence were more likely to be depressed than healthy

controls. Glioma patients had similar overall quality of life scores to patients with chronic neurological disease. However, overall quality of life was poorer in recurrent glioma patients compared with those people with stable disease involved in Giovagnoli's initial study (Giovagnoli, 1999).

Another study of low-grade glioma involving 39 patients suggested a similar relationship between emotional functioning and quality of life (Gustafsson et al., 2006). Patients reported lower scores associated with cognition, self-reported role and emotional functioning, placing more emphasis on these dimensions of quality of life than physical and social functioning. Patients had a reasonable overall physical functioning ability with the majority suffering from only minor restrictions if at all but did suffer poor cognitive function. Patients rated problems with fatigue, sleep disturbance and pain above other symptoms, supporting Lovely *et al* and others' findings of an association between fatigue and quality of life (Lovely et al., 1999, Pelletier et al., 2002, Brown et al., 2006). Global quality of life scores were low in 45% of participants although no one rated their quality of life as 'very poor'. Quality of life was significantly related to fatigue, emotional functioning, physical functioning, social functioning, cognition, pain and role functioning. Age, sex and marital status weren't related to quality of life in Gustafsson's study.

This section has specified a number of different approaches to the measurement of quality of life. Problems with this area of research include: diversifying number of instruments; lack of disease-specific tools; lack of examination of change over time; and small samples sizes, although certain studies and discussions have attempted to add clarity to the debate (Salander et al., 1998, Weitzner and Meyers, 1997, Heimans and Taphoorn, 2002). While quality of life tools may prove useful in clinical settings, the use of a reductive instrument may not be the best way to capture an individual's subjective experience of illness through research. More detailed interviews are required in order

to fully understand patients' concerns and how best meet their needs (Lyons, 1996), as the present study adds.

There is scope for an interesting discussion on the overlap between measures of quality of life, distress and supportive care needs⁶. To a certain extent, one appears to have evolved into the other albeit not in a linear or coherent fashion. From a sociological perspective, these constructs may reflect a particular trend in health services research and provision. Multiple definitions and approaches mean that a coherent meaning that can usefully translate into standard clinical practice could be lost.

2.4.7 Carers

The needs of carers may be different to those of the patient – they often have different levels of awareness, information needs and are thought to experience higher levels of distress than the patient themselves e.g. (Davies et al., 1996b, Salander and Spetz, 2002). Keir *et al*, using the Perceived Stress Scale, found 72% of carers of brain tumour patients reported elevated levels of stress, particularly younger, more educated carers and those caring for patients with lower grade tumours (Keir et al., 2008a). Differing relationships with patients, approaches to coping, the strain of dealing with personality changes; and ability to get on with normal life were all related to carer distress (Salander, 1996).

Sherwood and colleagues in the USA have also looked at carers' experience (Sherwood, 2004, Sherwood et al., 2004a, Sherwood et al., 2004b, Sherwood et al., 2006). Analysis of written accounts from 43 carers of brain tumour patients who attended a support group or bereavement group identified varying dimensions to the role: physical and personal care; responsibility for activities of daily living; coordinating information; running the

⁶ which extends beyond the remit of this thesis.

household; decision-making; providing emotional support and a peaceful transition into death including funeral arrangements and getting affairs in order (Sherwood et al., 2004a). Caregiving was mentally and physically exhausting and carers struggled to balance caregiving with other demands in their life such as caring for children. However, positive aspects were also emphasised and carers reported feeling privileged to look after their loved one. Carers relied upon friends and family for practical help as well as emotional support and respite and were angered by unsupportive interactions. Formal support from health care providers was also central to caregivers' coping but was not always viewed positively. Hospice services were regarded as a lifeline for carers but on occasion people had difficulty accessing the services when they needed them. Carers did not feel that they got adequate information, guidance and support to manage the patient's illness at home, particularly with personality and behaviour changes in the patient, associated with depressive symptoms (Sherwood et al., 2004b). Many caregivers actively sought information and researched treatment options, including experimental treatments.

Sherwood *et al's* findings are based on a retrospective analysis of bereaved caregivers' accounts, meaning that narratives are perhaps not an accurate reflection of the pertinent issues at a particular time, inevitably focusing on the latter period of illness (Sherwood et al., 2004a). Moreover, accounts were derived from a select sample of people attending support groups. However, they do provide a focus on carers' own needs and concerns, a valuable insight in planning support services for carers of people with a brain tumour.

Schubart *et al* identified unmet needs among 25 carers (seven male, 18 female; aged 37-72) of people with a brain tumour at various stages of their illness (Schubart et al., 2008). Needs varied at different stages of the illness. Around diagnosis, carers' sought information about the specific diagnosis and recommended treatment from health

professionals, friends and family, and the internet. Retaining the information was difficult around the time of diagnosis as a result of the shock, and recordings of consultations are thought to help (Fallowfield, 1993). Carers felt they lacked skills to adequately care for their loved ones and required guidance in this area. However, there was overall satisfaction with the care provided and rationalisation of the problems encountered. Information needs changed as the illness progressed, moving from detail of the illness and treatment, to guidance on the role of caring and managing challenging symptoms at home and what to expect in the future. Other themes identified from the interviews included family issues; managing challenging behaviours and depression; dealing with personal feelings; and navigating through the health system. Schubart *et al* commented on the changing nature of information needs as the illness progressed and the need to match resources to these needs, particularly in the early phase.

Soothill *et al* studied the unmet psychosocial needs of informal carers of people with a cancer diagnosis at different stages of their illness in a survey of 195 carers and interviews with a sub-set of 32 (Soothill *et al.*, 2001b). Forty-three percent of carers had significant unmet needs, more than the cancer patients themselves (Soothill *et al.*, 2001a). Carers' most important concerns were being addressed, but a number of less important unmet needs remained. The needs identified were diverse, including help with: considering sexual needs; financial matters; dealing with tiredness; and maintaining a sense of control in life. Help dealing with the unpredictability of the future was the most significant *unmet* need rated by 55% of carers, followed by help dealing with sadness and fears. Carers who were not the partner or spouse of the patient; those who had other care demands in their lives; those who did not have help from family and friends; and those who were caring for a patient in the palliative stages of illness had the most unmet need. Like the patient themselves, psychosocial needs were unmet.

As Salander has shown, carers can ally their own approach to dealing with the diagnosis with the approach of the patient (Salander, 1996). However, in order to understand how best to support carers in their role, it is important to tease out what their own most important concerns are, as I have attempted in the present study.

2.4.7 Spirituality/ existential issues

Spirituality and existential issues are of increasing interest in recent years. The literature in this area appears dominated by articles looking at these issues around death and dying – a time when people reflect on their lives and question their existence - but also examined spiritual distress and the role of meaning in coping with illness. Articles representing these issues are discussed in this section to explore the potential role of existential issues in the present study.

Adelbratt and Strang looked at the role of spiritual and existential concerns when dealing with the threat of death in a group of brain tumour patients and their spouses (Adelbratt and Strang, 2000). Death anxiety was related to shock, despair, anger, fear, uncertainty and sadness in dealing with their situation. Fear of death was often embedded in other fears, such as fear of surgery or treatment. Few people talked of life after death but those who did believe felt a sense of comfort from this. Concerns about separation from loved ones, particularly children, caused existential anxiety.

Participants in the later stages of their illness were more likely to have accepted their circumstances but felt an existential pain and sadness that their life was coming to an end. In their struggle to make sense of dying, people made contrasting statements, one minute talking openly about impending death and the next talking about the future or claiming they never thought of death and then saying it was always on their minds,

potentially related to Salander's concept of cognitive manoeuvres for coping (Salander et al., 1996). Proximity to death led people to re-evaluate their priorities and for some was an enriching experience. For others life became meaningless. Spouses already grieved the loss of their loved one as they knew them, particularly when personality changes took place, but felt a strong responsibility to care for them. In addition, spouses were more likely to accept their situation and prepare for the death of their partner before the patient did, reflecting on their own morbidity and survival as a result.

As discussed in section 2.4.3.2 in relation to coping, Strang and Strang reported comprehensibility and meaningfulness in relation to 22 brain tumour patients' and 16 carers' existential concerns (Strang and Strang, 2001). Comprehensibility referred to cognitive processes in making sense of illness, through accumulated knowledge, to understand why it had happened and why to them – knowledge was important and uncertainty led to lack of control and anxiety. Meaningfulness related to people's motivation to cope: enriching relationships with children and family members, music, work and hobbies that gave meaning to life. Re-evaluation of priorities helped people accept their circumstances and led to strength and positive outlook. A struggle to find meaning was associated with problems adapting to one's illness, poor physical health, personality changes, financial difficulties, strained relationships and fears about death. Although very few participants were religious in the traditional sense, many described a spiritual or existential experience that helped them create meaning. This involved a belief in a higher force, a power beyond themselves; destiny; life after death; the goodness of life; the grandness of nature; or personal inner strength, as reported in relation to coping (Sand et al., 2009). People who possessed a fighting spirit had faith and hope and were able to cope relatively successfully with their illness.

Existential support has been examined in 20 brain tumour patients, 16 carers and 16 nurses (Strang et al., 2001). Nurses associated existential support with religion followed

by a broad awareness of psychosocial and emotional support needs to assist patients in answering 'why?' and finding meaning in their experience. Listening and letting people talk was key, but nurses stressed that it was important to refer on to an appropriate professional if necessary. Nurses reported lack of time; feeling it was not part of their role; patients not raising existential issues; lack of skills and training; and difficulty with discussing sensitive issues as barriers in offering existential support. Patients valued the opportunity to talk about their existential concerns, such as uncertainty, talking about death and summing up one's life, with implications for life review or 'dignity therapy' (Chochinov et al., 2005). Patients valued being listened to, acknowledged and comforted in times of existential distress but didn't feel staff were approachable and didn't want to consume resources. Carers had information and support needs and wanted recognition and to be allowed to talk through their own existential crisis. Family members did not expect existential support but those who did were upset by the lack of it.

Spiritual needs were identified in lung cancer and heart failure patients followed qualitatively over time, expressed in terms of frustration, fear, hurt, despair; feeling life is not worthwhile; feeling isolated; useless; lacking in confidence; relationship problems; losing control; asking 'where do I fit in?' and 'what have I done to deserve this?' (Murray et al., 2004). Spiritual well-being was expressed in terms of inner peace; having hope, goals and ambitions; a social life and place in the community; a feeling of dignity and individuality; feeling valued; coping with emotions; communicating with truth and honesty; practising religion; and finding meaning. The trajectories of spiritual distress for those with a lung cancer diagnosis were different from those with heart failure, suggesting spiritual needs vary across patient groups, with implications for targeting appropriate services (Murray et al., 2007).

Increased time and resources devoted to addressing existential and spiritual concerns and developing health professionals' communication skills to interact effectively with patients is needed. Interestingly, Salander challenges the use of the concept 'spirituality' as another term for existential issues, arguing that the term has no theoretical basis and confuses understanding, instead suggesting that the phenomena be explained in the context of existential philosophy and psychosocial theory (Salander, 2006).

2.4.8 Palliative care provision

Research suggests that brain tumour patients are less likely to be in receipt of specialist community palliative care than other forms of cancer (Addington-Hall and Altman, 2000). Unique symptom control problems and complex physical, emotional, psychological and spiritual concerns calls for a multi-disciplinary approach to best support patients (Taillibert et al., 2004, McNamara, 2008). This section represents an important dimension of the illness experience and summarises the palliative care issues for glioma patients in the context of palliative care services more generally.

A hospice case note review of palliative care for patients with a primary malignant glioma looked at service utilisation and support, particularly for carers looking after a loved one at home (Faithfull et al., 2005). Referrals mostly came from hospitals (79%) followed by primary care (21%) and were reasonably quick with an average of 3.6 months (range=1-21) from diagnosis. The majority of referrals were for community-based care (90%) rather than in-patient admissions, suggesting that most people were cared for at home. Problems for carers noted in patients' notes included finances, difficulty coping with complex symptoms (e.g. seizures, hemiparesis and personality and behavioural change), having ill health, older age and other dependents although

these may not be an accurate reflection of the range of carers' issues and support needs. A service review showed hospice admissions for symptom control (n=4); terminal care (n=10); respite (n=5); and psychosocial crisis (n=2). Twenty-nine (74%) patients were admitted to other acute hospital inpatient services, many with more than one admission for reasons unclear. 30 patients (77%) attended outpatient appointments, mainly at the hospital. 72% used district nursing services and 23% other community-based nursing services. A small proportion (15%) used Marie Curie sitters; 21% used the day hospice; and 5% private nursing. Over half of patients had seen a social worker (54%); 46 % had contact with social services; and 26% received complementary therapy. While a large proportion (65%) had been seen by a speech therapist, there was no record of contact with any other allied health professional. In terms of psychosocial support, 8% had used counselling services and 31% the chaplaincy, but there was no record of support group attendance. However, it is important to consider that case notes are not an accurate source of information, requiring a more in-depth exploration into services and needs.

There are a large number of studies in palliative care reviewing services and exploring ways to improve care for people at the end of life. Research in this area has explored improving information and communication (Ashby and Dowding, 2001); specialist palliative care provision and expectations (Kristjanson et al., 2001, Taylor et al., 2001, Davies and Higginson, 2005); out-of-hours services (Worth et al., 2006); issues surrounding dying in the community and at home (comparing cancer provision to non-malignant disease) (Addington-Hall and Altman, 2000, Exley et al., 2005, Gomes and Higginson, 2006, Barclay and Arthur, 2008); and palliative care services in primary care (Shipman et al., 2008a, Murray et al., 2008). In recent years, more attention has been paid to the psychosocial and spiritual needs of glioma patients amidst a growing public interest around dying at home, raising awareness of death in the community. This increasing emphasis on palliative care research is set against a backdrop of government

guidance and initiatives to improve services (Department of Health, 2001b, Department of Health, 2008, Scottish Executive, September 2008).

2.5 Summary

A very broad and complex literature base informed this enquiry and understanding of living with glioma. Interwoven bodies of literature around diagnosis; information and communication; coping and psychological symptoms; quality of life; staff and service provision; interventions to improve services; spirituality in health care; carers' needs; and an increasing wealth of palliative care studies. Currently, there is little in-depth exploration of psychosocial needs over time of people affected by glioma or enough research exploring patient perspectives in general (Kearney et al., 2003). The current study adds insight into practical, social, psychological and spiritual needs from the perspectives of glioma patients, their families and professionals involved in their care.

Chapter Three: Methodology

3.1 Introduction

When planning and designing this research study, it was important to consider all possible approaches and methods that best answered the research aims and sat well with the research philosophy. There were also a number of practical, methodological and ethical issues to explore in order to produce a sound study design possessing integrity. This chapter documents the process of designing this research project and outlines the chosen methods with a justification for each choice.

3.2 A qualitative approach

A qualitative approach has become accepted as valuable in medicine and clinical practice to answer certain research questions. A quantitative approach answers ‘how many?’ and makes suggestions of probability and likelihood but does not necessarily unpack how and why a particular phenomenon has arisen. Quantitative methods are concerned with statistical association and the requirement to reduce confounding variables in order to maximise purity of the method and eliminate context. Qualitative inquiry gives credence to the social and cultural context that quantitative research considers a confounding variable (Murray and Chamberlain, 1999)⁷. Use of a qualitative approach has helped to develop in-depth theoretical understandings that contribute to the evidence base in clinical practice (Barbour, 2000). As Crouch and McKenzie argue in

⁷ Murray and Chamberlain provide a useful overview of the qualitative and quantitative debate. Murray, M.; Chamberlain, K. (1999) *Qualitative Health Psychology: theories and methods*. London: Sage.

favour of research with a small sample size, depth of meaning overrides the need for a large numbers of cases (Crouch and McKenzie, 2006). Using this approach has facilitated detailed analysis of the holistic dimensions of illness experience firsthand, helping to develop a conceptual and theoretical understanding of living with the disease and presenting views on ways to improve services and meet needs.

3.2.1 Ontology, Epistemology and theoretical perspectives

When choosing qualitative methods, it was important to consider and adopt a philosophy or theoretical perspective about how the subject of inquiry is made meaningful. The theoretical perspective was in turn informed by an ontological (philosophical theory about the nature of existence) and an epistemological (philosophical theory about what can be known about the world) stance. The approach to a research study and the methods chosen are underpinned by beliefs about our social world and how it can be interpreted. Traditional positivist science is driven by an objective epistemology, dictating that reality can be studied and reported on directly (Crotty, 1998). A subjective theoretical perspective specifies that meaning is wholly generated by the subject with no interaction with any external reality. According to this perspective there is no scope for a joint construction of meaning between subjects. A constructionist stance gives weight to the interaction between the subjective (our internal perceptions, thoughts, values and beliefs) and the objective (the world around us and others in it). 'Reality' or 'multiple realities' are therefore more appropriately regarded as constructed in the interaction between the researcher and the researched (Murray and Chamberlain, 1999). Although qualitative methods can be used in line with a positivist stance, it is the rich interactions rooted in a social, historical, political and temporal context of interest to the constructionist that can be studied in detail using qualitative methods. Furthermore, it is impossible to be value-free and fully separate the phenomenon under investigation from its context (Gergen, 1973).

While the extremes of the objective and subjective epistemological positions are problematic and would not 'fit' with certain theoretical perspectives and methods (the arguments for which are beyond the scope of this thesis), a realist ontology (view of reality) need not exclude an interpretivist epistemology (attention to context) and the use of qualitative methods. There is a distinction here between the real world physically existing beyond the conscious mind and the ability to ascribe meaning to that world. How one comes to know the world is determined by our interaction with it and the meaning we construct (Crotty, 1998). There is a middle ground (which I have adopted) to understanding the philosophical debates underpinning social research that makes research possible (e.g. Silverman, 1993, Seale, 1999b). This approach valued the context surrounding person-centred accounts and did not allow the complexity of theoretical debates to constrain the research agenda and the possibility of commenting on phenomena. Being clear about the approach used allowed the analysis to be interpreted in a way that is meaningful. Producing a good quality, rigorous design and analysis while engaging in reflexive practice also helped strengthen the study (Seale, 1999b, Barbour, 2008b).

Barbour argues that a definitive typology of the different approaches is elusive so that you never arrive at a distinction between the different traditions (Barbour, 2008b). Nevertheless, it was important to learn about the various approaches and choose one or a combination that sat well with the way I, as the researcher, saw the world and the people acting in it. Seale argues that we are not expected to be able to answer major philosophical questions about the nature of reality before research can proceed. He suggests that social scientists can be pragmatic about drawing a line under the debates in the same way that we 'bracket out' deeper existential or ontological questions in our every day life in order to get on (Seale, 1999b). As Murray and Chamberlain quote Becker (Becker, 1963) as saying, these debates should not 'paralyse' much needed

research (Murray and Chamberlain, 1999)). Barbour cites Seale as likening philosophical endeavours to '*time out in the brain gym*' [P: ix] [Seale (1999) and while worthwhile to consider one's position, it is not something that should preoccupy the research process.

3.2.2 Carving out a position

Whilst it may not be necessary to subscribe *fully* to one epistemological or ontological position, it was useful to reflect on my thoughts about how I saw the social world and the influence this had on approach to research. It also provided a context in which the outcomes of a research study were interpreted (Crotty, 1998). There was a more neutral way of thinking about the social world and a kind of objective reality. I would not argue that the physical world does not exist beyond our sensory perception of it. Our perceptions are guided in part by human biology and the laws of physics. However, I would argue that our understanding of and the meaning we ascribe to what we see and experience is influenced by existing theory, knowledge, experience (including interactions with our social world and others in it) and 'personal biography', which in turn are shaped by socio-cultural and political factors. Seale (Seale, 1999b) supports the 'middle way' described by Martin Hammersley which allows for us to 'know' a real world and to share that knowledge with others (Hammersley, 1992). The 'third world' of shared knowledge was a product of joint endeavour in the research interaction. Although that world did not necessarily come into existence through use of language to describe it, looking closely at interview text enabled me to tap into experience.

I was sympathetic to a broadly (social) constructionist philosophy and interpretivist perspective (see Crotty, 1998, pp1-17 and pp 42-65)). This approach allowed me to explore the 'micro' level of individual experience while giving weight to the 'macro'

structures influencing people that were interrogated through theoretically informed sampling (Barbour, 2008a). I adopted some of the principles of the constructed grounded theory approach (Charmaz, 2006) and borrowed particular techniques for sampling and analysis (see section 3.2.5 on sampling and 3.2.12 on analysis for explanation). ⁸However, as Seale suggests, I used the different philosophical positions as a resource rather than a ‘foundation from which the methodology proceeds’⁹ [P26] (Seale, 1999b).

3.2.3 Methodology

Within qualitative methods there are a number of options to choose from and a plethora of handbooks and guidance. Often a theoretical approach provided a prescription for how to conduct the research although one theoretical perspective did not necessarily go hand in hand with a particular methodology and set of methods¹⁰ (Crotty, 1998). Often the techniques adopted by researchers are not consistent and the terminology of different approaches is applied variably. For example, as has been outlined in the literature, many researchers make claim to a particular methodological approach, most commonly grounded theory, without making it clear what had actually been done (Lingard et al., 2008, Dixon-Woods et al., 2004b)). Originally developed by Glaser and Strauss (Glaser and Strauss, 1967), the more commonly adopted approach

⁸ This approach to grounded theory embraced the social constructionist perspective and gave consideration to subjective experience and multiple realities led by particular beliefs, values and world views compared to Strauss and Corbin’s more singular approach to the method (Cresswell, 2007).

⁹ Seale argues for relative autonomy of research practice from philosophical and political debates.

¹⁰ Where methodology refers to the theoretical stance and methods refers to the actual techniques used.

in recent times is the highly prescriptive methods of Strauss and Corbin (Strauss and Corbin, 1998) or other adapted methods e.g. (Charmaz, 2006). However, what I believe is more realistically the case is that methods adopted by researchers are informed by a number of different approaches.

In an attempt to 'stimulate methodological awareness' (Seale, 1999b), I reflected on various different approaches to research and methodologies. Certain approaches considered did not resonate so well with the aims and design of the study although there was a great deal of overlap and many of the core principles (such as an iterative process and attention to context) were shared by a variety of approaches. However, I considered that the phenomenological (Hopkinson, 1999) and ethnographic approaches e.g.(Reeves et al., 2008)) were considered better suited to a small number of cases that could be explored at a much higher level of detail.

In terms of methods, an observational study was ruled out as it would not allow such a level of insight into personal experiences as that given via personal report as well as practical problems of gaining access, exploring experience over time and ethics committee requirements constraining the naturalistic setting (Barbour, 2008a). Methods such as those within ethnography (Reeves et al., 2008), narrative inquiry (Reissman, 1993) and discourse analysis (Potter and Whetherall, 1987) are more focussed on the function and purpose of human actions and are perhaps more suited to studies of identity, social practices and power dynamics. While it was useful to study these functions as part of the context in which an account was given, the methods within grounded theory gave more of a voice to the content of *what* was being said rather than *why* it was being said. However, the principle of experiences coming alive through language and story-telling used in narrative inquiry was a broadly useful principle I abided by (Reissman, 1993). Group interviews were not considered appropriate. While they need not exclude the possibility of talking about sensitive issues, indeed some

people may benefit from the supportive environment, there was potential for upset if topics are broached that certain individuals were not comfortable with. Furthermore, there was the risk of disclosures around issues such as prognosis and life expectancy which some respondents may not be aware of or want to hear.

The iterative approach to recruitment and analysis offered by grounded theory fitted well with the exploratory nature of the study. The traditional grounded theory method requires that you start from as close to a 'tabula rasa' as possible and allow new themes to emerge and evolve from the data without imposing too rigid a framework upon the data. However, I would suggest that is impossible not to be informed by your existing theory, knowledge and personal biography, and this is precisely the kind of self-awareness cultivated by reflexive practice. Charmaz's use of grounded theory was more fitting for use with a social constructionist understanding of human experience. Within this approach, the constant comparative method of analysis was used, allowing a broader comparison across cases at various times in the illness trajectory; thus meeting the core objectives of this study.

With any form of interpretive qualitative inquiry, the report on personal accounts is inevitably a second order construct rather than a direct representation, but it enabled an emphasis on personal experiences that can inform practice and enhance psychosocial and supportive care. Inevitably, as discussed in relation to reflexivity, there was some level of 'me' as the researcher in the interpretation of participant accounts but following the techniques of coding and comparison prescribed by the methods of a grounded theory approach provided transparency. While the statistical generalisability of findings was not an aim of this research, through conceptual and theoretical development, findings are transferable to understanding the experiences of people with the same or a similar illness, referred to as 'theoretical generalisability' e.g.(Barbour, 2008c, Seale, 1999a). Outcomes were suggestive rather than conclusive and provided a

plausible and helpful way of viewing experience rather than the 'one true way' of seeing things [p13] (Crotty, 1998). When reporting on findings, it is not possible to precisely quantify how often complex issues arise, nor is it an aim of the study, which instead seeks to understand the nature of these issues. However, in natural language use, particular weight can be given to indicate more prominent concepts or the strength of a view (based on the researcher's interpretation) with use of certain terminology such as 'many', 'most' or 'few' to summarise participants' responses. Moreover, it allows the researcher to flag up disconfirming data that appears in the minority. There is some consensus on the interpretation of these summarising terms (Aronson, 2006), and they have arguably come to be accepted terms for use in qualitative research (White et al, 2003; Ch 12 Barbour, 2008d).

Use of the grounded theory method here was in part due to the fact that the method is widely known and has become accepted within the field of medicine through publication in peer-reviewed journals. Some of the principles of narrative inquiry were also adopted to understand how the use of language gave meaning to experience and to my own role in collaboration with the respondents within a particular context. The study also benefited from some ethnographic and observational techniques indirectly through attendance at clinics and support groups and collection of patient information leaflets and other documentation and these are not to be underestimated in terms of 'setting the scene'.

3.2.4 Qualitative interviews

I concluded that in-depth semi-structured qualitative interviews were the best method of data generation for this particular study. A semi-structured interview gave participants a chance to tell their story in their own words without too much limitation

(Gysels et al., 2008b). Multi-perspective interviews over time also gave a better insight than 'one shot' single interviews (Pope and Mays, 2009, Kendall et al., 2009, Murray et al., 2009). Most significantly, semi-structured in-depth interviews gave rise to the kind of rich accounts with room for context setting that is invaluable in this kind of exploratory research. I visited people in their own homes, on their own terms and in familiar 'safe' surroundings. People opened up their lives and shared them for a time, putting me in a very privileged position of insight. The intimacy of one-to-one or paired interviews facilitated discussion of sensitive issues around diagnosis and prognosis and yielded a personal account of experience.

Talking was a practice familiar to participants and not as draining as, for example, lengthy questionnaires or complicated instruments (Harris et al., 2008), which were not considered as useful when broaching sensitive topics with an ill population (Davies et al., 1998). I considered a questionnaire approach overly reductionist and simplistic as well as potentially intrusive as a method for this particular study. Semi-structured interviews allowed the direction of the topics discussed to be guided by the interviewee, which was most suitable for such an exploratory study broaching potentially sensitive and upsetting issues.

If a patient died during the study, a sympathy card was sent to their family member, and contact was made three months later. If agreeable, a follow-up visit and bereavement interview was conducted. I felt that a bereavement interview, although not something that every person might feel comfortable with, was an important way of monitoring how carers were coping and provided a sense of closure to their research experience.

Qualitative interviews were also conducted with patients' general practitioners, occasionally by telephone. Once patients had progressed through their initial treatment at the hospital, contact was made with their GP to ask if they would take part in a brief

interview about their role in the care of the glioma patient. Similarly, one-off interviews were conducted with a wide range of other health, health-related and social care professionals working with glioma patients (see Appendix Nine for recruitment letters, Appendix Seven for information sheets and Appendix 10 for interview schedules). Consent was taken from each professional before interviews proceeded (see Appendix 11 for consent forms).

3.2.4.1 Timing and content of interviews

The timing and content of interviews was guided by ethical considerations, as well as being set by the research agenda. The topics explored in interviews were selected based on the psychosocial oncology literature, a pilot consultation of brain tumour patients and professionals, and a holistic model of the illness experience. Some of the issues had greater potential for distress such as discussion of emotional and psychological concerns, existential or spiritual concerns and issues around death and dying. It was important to allow discussion of these topics to be guided by the participants rather than forcing them to talk about subjects they found too distressing or were not ready to broach. Accordingly, exploration of these issues was based on cues from participants (Kendall et al., 2007).

Although, as mentioned in the previous section, interviews were guided to an extent by interviewees, an interview schedule was developed as a loose guide in conducting interviews (see Appendix 10). The topics were chosen based on a small pilot exercise involving a discussion with two existing brain tumour patients and consultation with the neuro-oncology team and a neuro-oncology support group. Figure two provides an overview of the multi-dimensional model of the issues used to guide interviews.



Figure 2: The Holistic Dimensions of the Illness Experience

At times of crisis or acute illness, interviews were postponed to allow participants to have time to come to terms with what had happened. Thus, a period of at least one week was left after diagnosis and a period of three months after a bereavement before contact was made.

3.2.4.2 Qualitative longitudinal (QLL) interviewing

While *quantitative* longitudinal methods are a mainstay in medical and health care research, the contribution of the QLL method has yet to be fully realised. Historically, there has been some use of the method combined with largely quantitative methods, for example, the Bangor Longitudinal Study (Wenger, 1999), although the approach is

more common in other disciplines such as anthropology (Kemper and Royce, 2002), education (Polard and Filer, 2000), social policy (Corden and Millar, 2007) and psychology (Hughes and Dunn, 2002)¹¹. However, there are a growing number of studies looking at the experience of illness over time (e.g. Murray and Sheikh, 2006, Kendall et al., 2006, Lawton et al., 2008, Lohne, 2008, Swallow et al., 2008, Worth et al., 2009). Close review of published work suggested that longitudinal techniques were used more widely than reported but the data is not necessarily used to explore change over time. Moreover, lack of clear key word identifiers meant that these papers were missed and authors are not clearly reporting the methods used to analyse the data e.g. (Grbich et al., 2000, Pollock et al., 2008). Within brain tumour research, there have been a small number of QLL studies e.g. (Salander and Spetz, 2002, Rijmen et al., 2008).

In a feasibility review, Holland and colleagues suggest that the method is useful for studies of process, transition, pathways, changes and adaptation as well as looking at complexity and context using a flexible and responsive design (Holland et al., 2006). QLL studies produce a vast amount of data and there is a danger of researchers becoming over-burdened. However, this method has a considerable amount to offer in understanding illness experience and careful study design can minimise this problem. The QLL method has been variously interpreted and employed by different disciplines: following up a particular community; individuals; a particular location or site; and research across the lifecourse where researchers have followed up families over a number of generations (Holland et al., 2006). There are a number of different methods for collecting data over time including life history, biography, diaries, scrapbooks, observation, case study and the main approach used in health services research

¹¹ These papers have been cited in a review of QLL HOLLAND, J., THOMSON, R. & HENDERSON, S. (2006) Qualitative Longitudinal Research: A discussion paper. *Working paper number 21*. London: South Bank University, Families and Social Capital ESRC Research Group..

including my own study: repeated interviews (Thomson and Holland, 2003, Thomson et al., 2003).

Examination of time and *change* over time is viewed as central to the conduct of qualitative longitudinal research (Thomson et al., 2003). As Neale posited at a recent conference examining the use of time in research (Neale, 2008), drawing on the historical 'Durkheimian' notion of time and more recently Adam's 'Timescapes' (Adam, 1995), time is complex: it is fluid, recursive, multi-dimensional and infinitely varied and experienced by us as human agents; an 'unpredictable passage through a changing environment'. Time is a backdrop for life events, turning points and critical moments or epiphanies. Illness is one such experience that locates a set space of time in one's life. One's temporal location is seen as significant in influencing the narrative accounts given in a research interview. One's past isn't fixed; it can be reinterpreted 'through the lens of the present day'. Furthermore, we have different orientations to the future. Stability and endurance over time is of as much interest to researchers as transitions and changes (Neale, 2008). In the context of the present study, orientation to the future and thoughts around time or lack of time were more poignant for those facing death.

Saldana, coming from a background in education and theatre, produced a textbook on the qualitative longitudinal method aiming to bring together some of the diverse interpretations of the method (Saldana, 2003). Saldana recognised that the application of the approach varied from discipline to discipline and depends on the particular research design and methodology in use. Saldana requires that participants are followed up over a long period of time for the findings to be meaningful. Duration and change are central subjects of the inquiry for true QLL methods to be employed; although time should not be assumed to be straightforward (Saldana, 2003). In contrast to Saldana's stated opinion, I agreed with Corden and Miller who suggested that the length of time the study needs to run for depends on the research questions

and the specific illness under scrutiny (Corden and Millar, 2007). I chose to conduct interviews with glioma patients over a period of about one year. While this was in part guided by the constraints of a PhD study, the length of time chosen reflected the median prognosis for patients with a high-grade glioma. What is more, glioma is a rapidly changing illness so experiences changed quickly such that pertinent concerns at one time were replaced by others.

Use of the QLL method employed in this study helped to capture the changes that occurred in a short time frame as well as enduring issues. QLL interviewing allowed respondents to be followed-up over time with a series of in-depth interviews, each building on the last, rather than a one-off snap shot of someone's experience. The QLL method enabled a picture of the dynamic illness experience to develop, to understand how individuals orientated themselves in time, transitions they encountered and elements that remained stable in their lives. It also meant the shifting context permeating the research interview was explored. Many of the ethical issues related to conducting research with human subjects were heightened (Corden and Millar, 2007). As Corden and Millar asserted, participants' in-depth process of self-reflection and awareness undertaken throughout a series of interviews can be powerful and the researcher has the responsibility to make sure their privacy and integrity are maintained (Corden and Millar, 2007).

3.2.4.3 The pre-diagnosis period

The pre-diagnostic period is of significant interest to researchers although notoriously difficult to capture prospectively. There is recognition in the literature that this is a very important stage in a person's illness and can influence their subsequent satisfaction (Leydon et al., 2003) and psychological adjustment (Soothill et al., 2001a). Using a

prospective longitudinal study design recruiting people before formal diagnosis enabled this very sensitive period to be explored and rapidly changing needs captured.

Ethical considerations in researching the pre-diagnosis period for persons with a suspected glioma were crucially important. There was a potential challenge with regard to participants giving informed consent thus agreeing to take part in a study exploring the experience of living with a brain tumour before they knew their own diagnosis. As discussed previously, patients were for the most part aware that a mass or tumour had been detected on a brain scan, but remained in the dark about whether or not the mass was malignant and the consequences of this. However, I was interested in their experience as a person being investigated for a brain tumour. They were accessing and moving through the system whether or not they turned out to have malignant disease. In this way, everyone was 'in the same boat' at this point and their views and experiences were equally valid regardless of their final diagnosis. I was therefore able to be candid about the reasons I was interested in speaking to them.

3.2.4.4 A multi-perspective approach

Using a multi-perspective approach - interviewing more than one person about their particular experience (in this case patients, informal carers, GPs and other health, health-related and social care professionals) - added a richness of insight into the contextual elements of experience as exemplified elsewhere in the 'illness experience' literature e.g. (Murray et al., 2002, Clayton et al., 2005a). It allowed me to situate views in the wider context of relationships as well as giving a more rounded, comprehensive and holistic view of the subject of inquiry. This approach highlighted differences in individual experiences and perspectives, with each person interviewed bringing their own 'take' based on their own bundle of experiences, prior knowledge and socio-

cultural position. In interviewing a patient and the main person sharing an experience with them, there were shared stories as well as contrasts, contradictions and gaps in their accounts. What was not said was often just as significant as the things that were discussed. Far from being considered a limitation, the differences in accounts were testimony to the richness of human experience and it was this kind of content which was analytically interesting. Identifying differences in accounts suggests that there is something to be gained from getting first person accounts rather than always relying on carers as a proxy, although use of proxy accounts is endorsed as a substitute in health services research e.g. (Brown et al., 2008). While triangulation of views did not aim to provide measures of external reliability or validity to findings (as in quantitative research searching for an objective truth), it encouraged reflexive practice and challenged assumptions about the phenomenon under study, thus developing a better quality analysis.

3.2.4.5 Paired versus separate interviews when interviewing dyads

Separate interviews are not necessarily the 'gold standard' and it depends very much on the aims and objectives of the research. Joint interviewing – interviewing two participants simultaneously - is a valid method of inquiry where researchers need to be responsive to the needs of both participants (Morris, 2001). Joint interviews provided a rich insight into shared experiences and had particular utility when patients had cognitive or communication deficits (Pratt, 2002). Joint interviews should be interpreted accordingly in analysis when compared to separate interviews (Gysels et al., 2008b). I would suggest that using a mixture of joint and separate interviews was not problematic since coming from a social constructionist stance when interpreting data meant that weight was given to the context in which the interview came about. Understanding the number of people who contributed to an account simply added

another layer to this interpretation. I allowed participants to choose if they wanted to be interviewed separately or together.

3.2.4.6 Exclusion and inclusion criterion

A number of inclusion and exclusion criterion were applied in the recruitment of participants with a suspected glioma.

Inclusion criteria were as follows:

- Persons undergoing investigations for suspected primary malignant glioma (including both high and low-grade tumours).
- Persons over 18 years of age with no upper age limit.

Participants were excluded in cases of:

- Persons with far diminished cognitive capacity so that they are unable to make an informed autonomous decision about taking part in the study.
- Persons considered too ill (including profound communication deficit) or too distressed as assessed by the clinical team involved in their care.

A policy of maximum inclusion was adopted to ensure that a range of views and experiences were explored and a low threshold was applied for participants with cognitive or communication deficits.

3.2.5 Sampling

Sampling in qualitative research does not seek statistical generalisability, but reflects the diversity within a group of people or the phenomena under study. Sampling is a crucial part of the research process and determines the ways the research questions can be addressed and the analytic potential of the data (Barbour, 2008a). The main form of sampling used was theoretical or purposive sampling. This method involved an

iterative process moving beyond initial sampling that expanded the participants chosen for inclusion in the study according to demographics or characteristics that were theoretically interesting to develop emergent theories. As Crouch and Mackenzie suggest, I was not looking for individual persons of a kind, with certain designated properties or variables, but rather 'variants of a particular social setting where respondents embodied meaningful links between experience and the social structure beyond' [P493](Crouch and McKenzie, 2006). Theoretical sampling contrasts with representative sampling in quantitative research which aims to generate a complete group from the outset that represents the population under study enabling the research to make statistical inferences generalisable to the remainder of that population (Charmaz, 2006)¹². Theoretical sampling continued expanding, explicating and refining categories or themes that emerged from the dataset until theoretical saturation was reached and no new information was available. At this stage no new participants needed to be sought. Another important aspect of theoretical sampling was to seek out 'deviant cases' that challenged emergent theories. Achieving a true purposive or theoretical sample is often elusive despite the best intentions due to the constraints of the recruitment process and other factors beyond our control and was therefore viewed as a potential tool to guide sampling choices. Moreover, reaching a point of theoretical saturation is arguably not achievable due to time constraints and pragmatic shortcomings of the sampling process (Barbour, 2008a)¹³. I think it was necessary to consider theoretical saturation in its context as part of the interpretive framework of the

¹² Charmaz gives an excellent account of theoretical sampling within constructed grounded theory in chapter 5 ('Theoretical sampling, saturation and sorting') of her guidebook CHARMAZ, K. (2006) *Constructing Grounded Theory: a practical guide through qualitative analysis*, Sage..

¹³ Barbour supports Richie's more accommodating version which views saturation as a 'point of diminishing return' RICHIE, J. & SPENCER, L. (1994) Qualitative data analysis for applied policy research. IN BRYMAN, A. & BURGESS, R. G. E. (Eds.) *Analysing Qualitative Data*. London, Sage

individual researcher and in this way no *objective* end point could be reached. However, adopting the principles of theoretical saturation allowed me to make full use of the dataset and make more useful inferences that possess theoretical transferability.

The actual method of sampling chosen was considered carefully depending on the setting and the type of participants recruited. In many cases, researchers need to be pragmatic about their choices (Barbour, 2008a). In cases where participants are hard to reach or the focus of sensitive topics makes recruitment very difficult, a snowball approach to sampling might be more fitting (where one participant leads to contact with another). Consecutive or convenience sampling also have their place here.

Malignant glioma is a rare cancer and a very difficult diagnosis to deal with, meaning recruitment was anticipated to be challenging and time consuming. There was not a readily available pool of potential participants to choose from. Potential participants became available slowly over a number of weeks and months and it was necessary to respond to the flow of patients and recruit when possible. In some ways, having patients present in this way reflected the iterative nature of the sampling process quite well.

An initial consecutive sample of five patients was collected. This informed the subsequent recruitment that attempted to diversify age and gender of participants to explore potential differences in the issues encountered. Subsequently, persons with a more unusual presentation that was challenging for the clinical teams were recruited. Attempts were made to include older persons who were not eligible for surgical treatment into the study but they were too frail and subsequently transferred away from the recruitment hospital and lost to follow-up. Similarly, patients with severe cognitive impairment and disturbance, while theoretically interesting for inclusion in the study, were not eligible as they were not able to give informed consent. Patients who initially declined to take part in the study were sought out for inclusion at a later

stage of the sampling process to ensure their views were not excluded. Persons with a suspected or confirmed low-grade glioma were also recruited in a subsequent wave of sampling to examine whether issues for this particular group differed from those with a high-grade tumour. It becomes clear then that while the intention was there to use sampling to build theoretical arguments, recruitment of certain groups – frail elderly and very ill patients and those who declined - was not possible.

Relatives were obviously recruited directly in relation to the patient recruited and so not sampled theoretically. Similarly, GPs were case-related. Other health, health-related and social care professionals, interviewed in order to understand the context of the service for glioma patients, were subject to some theoretical sampling. An initial diverse group of professionals were selected from the broad range of those working with glioma patients in the catchment area of the recruitment hospital. The sample grew as new issues were raised in interviews and other professionals and their work settings were opened up for exploration.

3.2.6 Recruitment and attrition

Having a well thought out moral and ethical recruitment procedure was important to ensure participant welfare and maximise recruitment and retention of seriously ill participants (Steinhauser et al., 2006a). Establishing a rapport early on was important for maximising retention of participants. Informal carers were also found to be a vital point of access to very ill persons (Steinhauser et al., 2006a). Having a longitudinal design where participants were relatively well when they were recruited at the beginning of the study facilitated access to them as they neared the end of their lives. It was important to plan for attrition by having a flexible study design that allowed for a high number of withdrawals (Bruera, 1994).

Participants were recruited through the neuro-surgical team (including the consultants, specialist nurse, nurse practitioners and junior doctors on the wards) at the study hospital (see Appendix Six for a flow diagram of the recruitment process). Patients were identified in the Department of Clinical Neurosciences rather than Oncology as not all patients were referred to Oncology for treatment. Working closely with members of the clinical team who knew patients' case histories and other information about their circumstances was helpful. Having health professionals as the 'face' of my study was eminently beneficial. They made the initial approach to potential participants and were familiar, credible and trustworthy, thus encouraging participation (Shipman et al., 2008b). I was then, by association, afforded trustworthiness. Regular visits to the neuroscience wards were made to see if any new patients had been admitted. Similarly, attendance at the weekly multi-disciplinary team meeting and other research and social events at the hospital helped me to become part of the team.

Having members of the neuro-surgical team make the initial contact and hand over an information sheet enabled potential participants to give verbal consent for me to approach them and gave them time to consider participation, minimising any sense of coercion (see Appendix Seven for patient and carer information sheets). They could also decline taking part to someone not directly involved in the research, in which case no further contact was made¹⁴. Once patients had given verbal consent, I made telephone contact or visited them on the ward to discuss the study further and determine whether they wished to participate. It was explained that the study would involve an initial interview and possibly follow-up interviews if they were agreeable. It was stressed that

¹⁴ Naturally, health professionals acted as gatekeepers, seeking to safeguard patient welfare, a role that should not be discounted.

people were under no obligation to take part and were free to withdraw at any time should they change their mind. If people agreed to participate, an initial interview was scheduled. After completion of each interview, participants were kept informed about the next step and I let them know I would stay in touch. Subsequent interviews were scheduled with participants with a confirmed glioma via telephone nearer to the time the interviews were planned. Contact was always made with participants' GPs if a large amount of time had lapsed since last contact to ensure that the participant was alive and well. Those participants whose diagnosis was not a glioma were thanked and it was explained that no further interview was needed.

Due to the short survival of people with glioma, considerable attrition was anticipated and accommodated in the study design. Where a participant withdrew from further participation after only one interview, another person was recruited in their place in order to help ensure that a level of theoretical saturation over time could be reached.

Full ethical approval was granted by the Lothian Research Ethics Committee and management approval was granted by the NHS Research and Development programme (see Appendix Eight).

3.2.7 Consent and capacity

Consent to take part in research interviews was a central ethical issue, further emphasised by *repeated* interviews with 'vulnerable' participants. Potential participants had all the information available to them about the study in which they were considering taking part so they could make an informed decision and have freedom of choice to have their voice heard. As Seymour argues, while gatekeeping may aim to

protect vulnerable people, it can ‘disenfranchise the voices of the very ill’ [P185] (Seymour et al., 2005).

Issues around capacity were particularly relevant to brain tumour patients who may experience cognitive deficit during the course of their illness. In the absence of express guidance for brain tumour patients, research in this area was informed by the dementia literature. The American Geriatrics Society (AGS) guidelines suggested that persons with dementia should not be excluded from research provided it is justified on scientific, clinical and ethical grounds; next of kin’s intimate knowledge should be used; and each person should be assessed individually¹⁵(Sachs, 1998). I used these basic principles while operating a maximum inclusion threshold.

Pratt also highlighted a number of important techniques for approaching interviews with people with dementia that were applied in cases of diminished capacity: provide simple and clear information; work closely with lay and professional carers; give constant reminders; use joint interviewing with loved ones to facilitate interviews; and apply maximum inclusion as declining cognitive ability does not preclude consent. Pratt found people with dementia were able to talk through thoughts, feelings, life experiences and needs with great consistency. In some cases, potential participants had diminished cognitive capacity affecting their memory, communication skills and ability to process information. It was important to consider what information was important for the aims of the study when recruiting and whether it was relevant or not that a participant may not be able to recollect precise dates, times and other details (Pratt, 2002).

¹⁵ These guidelines relate to trial participation and so the transition into qualitative social research needs to be taken into account.

Certain authors have argued for a more fluid consent process such as retrospective consent to reflect ongoing dynamics (Gysels et al., 2008b). Lawton questions whether informed consent can ever be fully achieved, particularly in social research where the study changes shape and the outcomes may differ from those originally planned for. Proxy consent and advanced directives are suggested as alternatives to one-off prospective consent (Lawton, 2001). Advanced directives for consent in my study with brain tumour patients would not be ethically possible as participants were not necessarily aware of the future implications of their illness. Instead, capacity was constantly monitored, both over successive interviews and within the course of an interview in some cases. Capacity to give consent was also continually assessed in collaboration with informal and professional carers. Participants were asked to give written consent at each interview rather than providing one-off consent at the outset, giving them repeated opportunities to withdraw from participation (see Appendix 11 for consent forms). I emphasised that interviews were anonymous and confidential. In cases where participants did have diminished capacity I asked during the course of the interview that they were still clear about why I was there and happy to continue the interview. I worked closely with patients' loved ones here to ensure they were happy to continue and could give a more subjective opinion on their relative's capacity.

3.2.8 Use of instruments

The use of a tool to measure psychosocial factors in the illness experience was considered. Tools such as questionnaires were considered too rigid and would set the agenda for the interviews. Furthermore, interviews were considered tiring in themselves and asking participants' to fill out lengthy questionnaires could add to their fatigue. It has also been suggested that long complicated questionnaires could be

intimidating for participants, particularly at a time when they are feeling unwell and potentially emotionally vulnerable (Dean and McClement, 2002, Soothill et al., 2001a).

I felt that instruments could not be used to comment on the quality of life or other factors of people with a suspected or confirmed diagnosis of glioma as a population because the relatively small sample size meant that there was not enough statistical power to afford generalisability. Tools to assess depression and anxiety were perhaps too focussed on maladaptive coping, an issue which fell outwith the scope of my own study.

The more fluid approach of interviewing allowed respondents to tell their story in their own words which sat more comfortably with an exploratory approach. As previously reported, Harris *et al* suggest that talk is something much more familiar to people, less invasive and can be engaged in upon their own terms (Harris et al., 2008).

However, there was some utility for use of a tool to monitor how people were coping to ensure that no harm was done during the course of their participation rather than as a component of the research. One such tool that I felt met this criterion was the Distress Thermometer.

3.2.8.1 The NCCN Distress Thermometer (DT)

The National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) was developed in the United States to screen for distress in cancer patients. Distress can encompass anxiety and depression as well as feelings of vulnerability and spiritual crisis. The tool has been found to aid the detection of psychological distress and can therefore activate further investigation and intervention where necessary (Kelly et al., 2006). The NCCN guidelines suggest that persons scoring five or above on the tool

should be referred for a more detailed assessment of distress. This tool covers a broad range of dimensions of distress more in keeping with the holistic approach to understanding illness (see Appendix Five for the NCCN Distress Thermometer and details of studies validating the tool).

The DT was used to monitor distress and assess any changes over time (but did not form part of the empirical data). In cases where patients had a score of five or above they were discussed, with participant permission, with members of the clinical team and considered for further assessment and intervention.

3.2.9 Quality in qualitative research

Given the highly interpretative nature of qualitative inquiry, it is often difficult to assess whether a good quality piece of research has been conducted. Having considered the debate on quality in qualitative research, a number of principles were applied in the conduct of this research study (See Appendix Four for details).

3.2.10 Reflexivity – where am I in the research process?

The process of reflexivity ingrained in a qualitative approach allows the researcher to consider in detail their own role in the research proceedings. Reflexivity refers to the process of reflecting on how one's own position and values impact on the conduct of research and its outcome, having accountability and as a means of 'deconstructing the research encounter' [P210] (Finlay, 2002). Central to the premise of reflexivity was that I, the researcher, was not passive in the conduct of research but an active participant making an inquiry. My own prior knowledge, background and socio-cultural situation influenced the construct of narratives (the stories told in the research interview), the

meaning ascribed to these and ultimately the way in which the interpretation and analysis proceeded (Crouch and McKenzie, 2006). How I presented myself (a psychologist, a researcher, a sympathetic listener) and how I was perceived by those I was interviewing, combined with how I perceived the interviewee (an ill person, emotionally struggling) and how they wished to present themselves, all factored to influence the account created in each interview. For example, I may have been perceived as a young female researcher, associated with both the hospital and the university, and these factors could have changed the way in which the interviewees chose to tell their story.

Reflexive practice becomes ingrained in the way research is conducted and permeates each part of the research process from planning, design, analysis and outcome. I used an interview diary or journal as one way of reflecting on my role in the research process to record first thoughts and impressions after each interview, in addition to reflections on myself during the encounter. I recorded instances where, for example, I had been particularly emotionally affected by an interview or felt that I had a particular influence on something that was said or not said. There were cases where I felt I was being given a particular account because I was a young female (see Chapter 11 for more discussion). There is a danger of self-indulgence and it is crucial to bring the research back to a more 'macro' level. Therefore, frequent de-briefing, research team and peer group discussion helped to objectify my thoughts.

Finlay provides a fascinating history of how reflexivity has evolved over the years and maintains that it is interpreted differently according to a researcher's discipline and

theoretical positioning (Finlay, 2002)¹⁶. However, deconstructing the research encounter too much can lead to an infinite regress that becomes meaningless (Finlay, 2002). There is debate, dependent in part on theoretical positioning, over the extent of the power of the researcher's role in the research process but it is unarguably present. Transparency and honesty about the researcher's role allows any research study to be understood in its context.

3.2.11 Transcribing

Interviews were transcribed verbatim and use of slang and colloquialisms were included to keep as close as possible to the original interview. Transcripts were anonymised by removing any indicators of participants' name or residence as well as any other names or places mentioned in interviews. Particular care was taken to disguise health professional interviews as the nature of some of their positions meant they were more easily identifiable. The approach chosen for transcribing can impact on the subsequent interpretation of the data and subsequent outcomes (Kendall and Murray, 2005).

Transcripts were checked against the digital recordings on a regular basis and close contact was maintained with the transcriber, who used specific guidance. A de-briefing session was also held with the transcriber to ensure that they had not been unduly affected by the sensitive content of the interviews, an issue that has been highlighted in the methods literature (Harris et al., 2008, Kendall et al., 2007, Seymour et al., 2005).

¹⁶ To read more about each of these positions and the process of reflexive practice in research more generally see FINLAY, L. (2002) Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2, 209-230.

3.2.12 Analytic process

Analysis of in-depth qualitative interviews was a complex process requiring close examination and exploration of the data in order to integrate and interpret what was there and develop a theory that moved the analysis beyond the descriptive. The methods prescribed by Charmaz's grounded theory were adopted (Charmaz, 2006). The central tenet of the grounded theory approach rests with the iterative process. This relates to study design, theoretical sampling and the system of analysis (Lingard et al., 2008), enabling a move from a descriptive classification of events to an abstract theory of the phenomenon that accounts for processes and relationships. The theory was grounded in the data, and not from pre-determined hypotheses and formulations¹⁷, by integrating and explaining the data (Ch 12 Murray and Chamberlain, 1999). The techniques of sampling, coding and constant comparison were used to assist in the analysis. Sampling, as previously discussed, is central to the research process and subsequent analysis (Barbour, 2008a). Essential features found in one case that are shared across cases mesh together to form a wider theory (Seale, 1999a).

3.2.12.1 Coding

Initial coding, or open coding as Strauss and Corbin referred to it, was undertaken by looking individually at a small set of transcripts to determine the content of interest (Strauss and Corbin, 1998). At this point in the process, it was important to examine carefully what was in the interview, avoiding temptation to 'jump ahead' to the next level. Charmaz recommends that the researcher "remain open; stay close to the data; keep codes simple and precise; construct short codes; preserve actions; compare data with data; and

¹⁷ As I have argued elsewhere, it is not entirely possible to remain completely value-free in the generation of themes in an analysis.

move quickly through the data” [P49] (Charmaz, 2006). Coding was therefore performed line by line or in small sections according to each event or incident to stay in the moment and also consider where the analysis was going, which in turn informed future sampling and analysis. Words or phrases that summarised what was said or an experience that was reported were identified. Sometimes ‘in vivo’ codes were used which involved lifting a word or phrase actually used by an interviewee that explained or described a phenomenon. Staying focussed on each individual transcript at this early stage of coding was important to avoid imposing prior assumptions or expectations on the data and allowing the key concepts to emerge. Becoming immersed in the data at this level also helped to avoid the influence of existing literature. Using reflexivity to attend to and ‘expose’ personal assumptions meant that I could assess whether I was coding as a result of my assumptions or because I determined that a particular phenomenon really was there (see section 3.2.10 on reflexivity). Discussing emerging themes with colleagues also helped to address this issue.

Initial coding was followed first by focused coding. Focused coding is more conceptual, directed at the development of more abstract themes that give rise to more generic categories. This stage of coding spread the most prominent or frequent initial codes across a larger dataset to identify what was there. A long list of ‘open codes’ were reduced by eliminating those that did not appear to be common or relevant, and merging similar concepts that could be usefully combined or summarised. Codes (or developing themes) were adjusted, refined or changed to fit the data as a whole as key features from each transcript were identified. ‘Deviant cases’, examples that did not fit with the existing codes, were sought in the sampling process to help test and refine the categories formed.

Axial coding involved creating a structure to the codes. By looking at how different categories overlapped and inter-related, relationships between categories began to form and a structure arose, giving coherence to the analysis.

Finally, theoretical coding was attempted to reach a more sophisticated level of codes that may be integrated into a theory (Charmaz, 2006). However, I personally find coding for this purpose a bit too prescriptive and think there needs to be an intellectual leap at some point in the process which helps you to arrive at a theory, discussed in the context of existing theory.

Please refer to appendix 13 for a copy of the coding framework.

In order to produce a good quality analysis, all of the dataset was used to the full, in relation to the themes focused on and the theory developed so that a level of theoretical saturation was reached and no new themes emerged. Codes were also tested by having other members of the research team review transcripts for the purpose of triangulation and cross-validation. Twenty percent of transcripts were independently analysed by three different researchers. A smaller subset was discussed in more detail by members of the wider project steering group. One team member was not involved in the analysis as a result of their direct patient involvement with participants in the study. While this process did not highlight any disagreements or generate new themes directly, it was a useful means to discuss themes and stimulate thinking to move the development of ongoing themes forward. For example, discussions of themes around coping with colleagues allowed me to see some codes identified in the context of existential and spiritual issues, subsequently informing the development of these themes. Similarly, discussions on coping and adjustment informed the development of themes in this area and helped to place them in a theoretical context.

3.2.12.2 Constant comparative method

Constant comparison was used in the coding phase of the analysis to examine the dataset. This technique involved looking for similarities, differences and omissions by comparing and distinguishing statements, sections and incidents in the text within an interview and across interviews (Charmaz, 2006). This method was also used to compare interviews with the same participant over time. Making systematic and sequential comparisons added structure to the process, making it more manageable. Categories were constantly refined and reassessed as new comparisons were made and new information came to light to ensure they still fitted with any new data collected in an iterative process.

3.2.12.3 Memo-writing

Memos were written as interviewing took place as well as during the coding process. Memos were later integrated into categories and formed the basis for conceptual and theoretical development and discussion when writing up (Charmaz, 2006). Memos recorded first impressions and developing ideas as the research progressed.

3.2.12.4 Generating theory

Seale discussed Glaser and Strauss' principle of theory shifting from the 'substantive', explaining phenomena of interest to the researcher, to a 'formal' theory, one that has been tested and generalised (theoretically) to other settings, thus broadening their scope (Seale, 1999a). As part of the analytic process, theories that emerged from interviews were related back to existing theory and other empirical studies and in so doing helped to develop the theory further and give it theoretical transferability to other settings. At this stage, it was useful to broaden the focus and revisit the literature

to assess where the current findings fitted and could be explained. This, combined with further inter-disciplinary discussion with members of the research team, assisted in considering higher order themes to explain and describe the data. For example, Bury's concept of 'biographical disruption' was found to usefully summarise a group of themes describing the impact of the illness on people's lives (Bury, 1982). Likewise, Salander's discussion of 'disavowal' helped to explain a phenomenon identified in relation to coping (Salander and Windahl, 1996). Finally, broader theories such as Brennan's model of adjustment became useful to place the findings in a formal theoretical context (Brennan, 2001).

3.2.12.5 Longitudinal analysis

Conducting longitudinal analysis required comparing interviews carried out over time as well as comparing interviews cross-sectionally. There were many different directions the analysis could take and no one set of guidelines exists on how best to conduct longitudinal analysis. For example, it was possible to look at the data cross-sectionally, compare cross-sections over time or look at the data as case studies over time. Analysis over time is more than a series of cross-sections, building into a more complex phenomenon interwoven with the surrounding context (Saldana, 2003). Saldana's textbook attempts to create coherent guidelines for doing longitudinal analysis. There are a number of suggestions for techniques including Miles and Huberman's approach of translating qualitative data into quantitative data in order to chart frequency of themes and discern change over time (Miles and Huberman, 1994). I feel (and Saldana suggests) that this approach is overly reductionist and loses the richness of qualitative data that gives meaning to individual experience (Saldana, 2003). However, it depends heavily on the aims and anticipated outcome of the study. Saldana reviews Strauss and Corbin's basic guidance on doing longitudinal research (ch 11, Strauss and Corbin, 1998). They suggest that the researcher examines the sequence of actions and

interactions that occur through time and discern theoretical relevance from what is 'repeatedly present, notably absent or newly introduced, accounting for conditions, consequences and contingencies' [P49] (Saldana, 2003). Saldana perhaps puts more emphasis on how change has occurred compared with Strauss and Corbin's emphasis on the process (Saldana, 2003). For longitudinal analysis, Strauss and Corbin suggested 'miniframeworks' or conceptual diagrams using the same principle as Miles and Huberman but perhaps not as reductionist (Strauss and Corbin, 1998). Saldana provides a series of useful questions for conducting longitudinal analysis which I have incorporated into my analysis using some of the principles of grounded theory (see table four usefully summarised in table form by a colleague Emma Carduff). Dey (whose views are reported by Saldana) criticises Strauss and Corbin for not taking enough account of the context, conditions and causes of a particular process (Dey, 1999). Perhaps a multi-perspective approach (patients, carers, GPs and other health professionals), as well as ensuring researcher reflexivity goes some way to alleviating this concern.

I decided to look at the data as a cross-section and then compared the themes emerging from each set of interviews at each of the different time points. In this way, thematic analysis was done for each group of interviews using the techniques of coding via constant comparison as outlined. However, as individual illness journeys did not necessarily adhere to a set formula or timeline, each experience was different. By looking at the dominant themes at any one particular time, it was possible to examine which of these were enduring and how they evolved over time. There was a balance between looking for exhaustive concepts to explore in the dataset and keeping a focus on the aims of the study to make analysis more manageable and allow a good quality in-depth analysis.

The issue of theoretical saturation also applied to longitudinal analyses so that no new themes were emerging from the comparison of interviews conducted at different times. In this way a level of ‘serial saturation’ was achieved.

Framing Questions These questions address and manage the particular contexts of the particular study’s data by locating them in a processual, ‘analytic ocean’.	What is different from one pool of data to the next?
	When do changes occur through time?
	What contextual or intervening conditions appear to influence and affect participant changes through time?
	What are the dynamics of participant change?
	What preliminary assertions about participant changes can be made as data analysis progresses?
Descriptive Questions To help answer the framing and analytic questions. These could be statistical number answers.	What increases or emerges through time?
	What is cumulative through time?
	What kinds of surges or epiphanies occur through time?
	What decreases or ceases through time?
	What remains constant or consistent through time?
	What is idiosyncratic through time?
	What is missing through time?
Analytic and Interpretive Questions This stage is towards richer levels of analysis. These are iterative and the answers may be revealed at any time.	Which changes interrelate through time?
	Which changes oppose or harmonize with natural human development or constructed social processes?
	What are the participant or conceptual rhythms?
	What is the through line of the study?

Table 4: Source: Ch 3, Longitudinal Qualitative Data Analysis in ‘Conducting qualitative longitudinal analysis’ (Saldana, 2003)

3.2.12.6 Use of Computer Assisted Qualitative Data Analysis Software

QSR NVivo version seven was used as a means of managing the large volume of data collected throughout the study (QSR International, 2006). This is a computer software package with a variety of functions and settings to assist with analysis. The more basic functions such as the coding facility, memos and annotations were utilised. NVivo was useful for storing the interviews together in one place and organising the text into coding categories that I devised and developed. Once the basic framework had been developed on paper, NVivo was used by putting the coding structure into the package alongside the interview transcripts and working through the transcripts manually coding relevant sections of each interview under the coding categories by simply selecting them. The software works in such a way that it stores the selected line or section of the transcript in a file under the relevant code. In this way, sections of the transcripts were organised according to the theme they applied and could be recalled and grouped together with all sections that were relevant to a particular theme or theory. The memo-writing function of NVivo stores the notes made alongside the codes and transcripts and allows links to be made between memos to form a structure and help theoretical development.

3.2.12.7 Feedback of information to participants

From an ethical point of view, participants in the study had a right to decide whether they would like to receive feedback about the findings of the study or not. However, this is further complicated as patients and carers may feel differently about this. Also, due to the nature of glioma, many patients did not live until the end of the study. It is possible that their loved ones may not want to receive a report on the findings as it may cause distress and cause them to revisit a time that they do not wish to think about.

Each individual participant was given the opportunity, when signing the consent form, to request feedback on the findings of the study. A separate summary document of the findings was produced. Participants will be contacted in advance of sending them a copy of this report to allow them the chance to reconsider depending on their current circumstances.

3.3 Ethics of research with people with progressive life-limiting illness

Conducting research with participants who are very ill and face diagnosis of a life-limiting disease heightens the need for ethical conduct and raises a number of new issues to be addressed. I have attempted to address as many as possible of the ethical issues likely to be faced when planning and conducting a research study with an ill population.

I have used the four principles of medical ethics, first developed by Beauchamp and Childress in the late 80s (Beauchamp and Childress, 1989), as a guide to thinking about ethical issues in health care and framework for decision-making to ensure participant respect and welfare. Gillon presents respect for autonomy, beneficence, non-maleficence and justice as a 'simple, accessible and culturally neutral approach' to considering medical ethics (P184] (Gillon, 1994), which I would argue can be applied in conducting research as well as medical practice. In research terms, it is not always possible to benefit individuals directly but researchers should endeavour to protect participants' welfare and avoid harm. Participants enter into the research process in the knowledge that they are not expected to benefit directly and it is a case of respecting their autonomy to do so (Gysels et al., 2008a).

3.3.1 Planning research with ‘vulnerable’ participants

Although the participants in the current study did not necessarily consider themselves as vulnerable, their illness positioned them in the hands of health professionals rendering them susceptible to decisions being made about their care and future, while enduring a devastating diagnosis. The research process could potentially bring thoughts and feelings to the fore that had been suppressed. Therefore, it was useful to consider the dimensions of the so-called ‘vulnerable patient’ that rendered them so and to employ measures to avoid participants’ welfare being violated.

There has been some debate in the literature about whether or not research should be done at all with very ill people ((de Raeve, 1994) vs. (Bruera, 1994)) that informed decision-making in the current study. DeRaeve opposes research with people at the end of their lives whereas Bruera argues that it would be ethically wrong to exclude very ill participants. While these authors write in relation to randomised controlled trials in research, this sentiment has been echoed elsewhere in relation to social research e.g. (Lee and Kristjanson, 2003, Harris et al., 2008). Helping the voice to be heard of people who are going through an experience informs the development of services for the greater good (Lee and Kristjanson, 2003). Moreover, there is an increasing body of literature suggesting that research participation can be beneficial for sensitive or vulnerable subjects (Kendall et al., 2007, Harris et al., 2008). There is evidence to suggest that participants find it helpful to talk about their experiences, unburden concerns and find contributing to help others an enriching experience e.g. (Ferrel and Grant, 2001); and very ill people are surprisingly willing to take part (Hopkinson et al., 2005). In a study with brain tumour patients exploring ways of improving care, Davies *et al* found that 63% of participants reported feeling comforted by the interview process while 5% did not enjoy the experience (Davies et al., 1998). Participants’ autonomy and right to make an informed decision about whether or not to take part should be respected.

3.4 Health and safety

There were a number of health and safety issues to consider both for the study participants and myself.

3.4.1 Participant welfare

Researchers have a big responsibility for the welfare of their participants and this involved making moral and ethical decisions throughout the course of the project. It was vital to ensure that participants were not being caused any distress or harm as a result of their involvement in the study, emphasising the need to monitor distress as previously outlined. Moreover, responsibility did not necessarily end when research interviews ended. However, as Seymour *et al* argue, there is a desire to be therapeutic in a research setting and in some way help participants rather than just listen and generate data that is difficult to balance (Seymour et al., 2005). Arguably the listening process in itself provided therapeutic benefit for participants (as detailed elsewhere) and therefore the interview process unavoidably serves as an intervention. In order to plan for extreme cases of significant distress, a suicide protocol was in place.

3.4.2 Researcher welfare

The responsibility for participant welfare was significant and can be a heavy burden for researchers. Often researchers are faced with moral or ethical dilemmas. In addition, there was potential for distress to be caused as a result of sharing, in part, a difficult and distressing time with all of the participants in the study and their families. Visiting people in their own homes; seeing how they live; their photographs; hearing their memories and life stories; and meeting their family members inevitably built a

relationship which was cultivated over time with repeated contact and visits. While professionalism is vital here, occasionally researchers may find it difficult to switch off from this distress and concern and begin to ruminate on it. This emphasised the importance of de-briefing sessions and supervision from senior colleagues. As Seymour asserts,

“Being a palliative care researcher involves making moral choices and facing dilemmas that require ongoing reflection and continuing support and supervision to resolve.” [p186](Seymour et al., 2005).

I was able to have regular de-briefing sessions with a clinical psychologist member of my research team. Use of an interview journal also helped with reflection and provided an outlet for any concerns. However, it is worth pointing out that interacting with very ill participants and conducting interviews which address sensitive and potentially distressing subjects was a humbling and enriching experience and was not as difficult as it might be assumed (Kendall et al., 2007, Hopkinson et al., 2005).

People engaged in social research also spend time travelling and visiting people in their homes. Clearly this signals a safety risk and appropriate steps were taken to ensure my safety while working alone or out of hours while at the same time preserving confidentiality – a difficult balance.

3.5 Summary of methods

Patients were sampled theoretically and recruited in a Department of Clinical Neurosciences. Patients were given information sheets giving details of the study and asked to consider participation. For those who granted permission, contact was made and an initial interview scheduled with those who agreed to take part. Contact was maintained with participants via telephone and follow-up interviews were scheduled

in this way when appropriate. Participants signed consent forms at each interview. Recruitment of GPs occurred, with patients' permission, after patients had completed their primary treatment so that GPs had the opportunity for more experience of caring for the patient. All health, health-related and social care professionals were identified and contacted by letter to determine whether they wished to take part in a brief interview.

In-depth semi-structured patient and carer interviews were conducted in a place and at a time convenient to them, usually in their own homes. Up to four interviews were conducted with patients and their carers: in the time leading up to diagnosis; around the time of starting treatment; after primary treatment has finished (radiotherapy and concomitant chemotherapy) and after a designated 6 month follow-up period. One-off GP and other health, health-related and social care professional interviews were conducted at participants' workplace or via telephone at a time convenient to them. Interviews were transcribed verbatim.

Data was analysed using the constant comparative method based on a grounded theory approach and assisted by qualitative data analysis software QSR NVivo version 7. This method involved reviewing a small set of interviews and looking for recurrent themes emerging from the data, moving back and forth between excerpts and looking for commonalities in an iterative process. Emergent themes were combined to form higher order constructs that described and explained the data. These themes were constantly refined, reviewed and amended as more data was generated. Deviant cases were sought to confirm or reject the emergent themes. Analysis was cross-sectional, across the interviews at any one time period, and longitudinal, looking for similarities and differences between interviews over the course of time.

Chapter Four: Participants and interviews

Due to the complexity of the longitudinal method used, this brief chapter aims to summarise the interviews conducted, giving an overview of the chronology used to inform the subsequent findings chapters.

Participants

A total of 26 patients referred with a possible diagnosis of brain tumour were recruited at times one, two and three. (14 males, 12 females, aged 21-76 median age 51 years). 21 were diagnosed with a glioma (14 males, seven females, median age 51 years) and the remaining five a non-glioma diagnosis¹⁸. Of these, 14 were diagnosed with glioblastoma multiforme WHO grade 4, two were diagnosed with intermediate grade anaplastic astrocytomas WHO grade 3, one person was diagnosed with an oligodendroglioma, two people were diagnosed with a low-grade astrocytoma, and two had no confirmed pathology but were diagnosed with a GBM and brain stem glioma respectively from imaging.

There were a total of 24 carers (10 males, 14 females). Their age was not recorded but the majority of carers were partners of the patient. Three parents took part and two daughters. Five patients had no carer available for interview. One of these patients lived alone. For three patients, more than one carer was interviewed on one occasion.

¹⁸ The diagnoses of the five patients without a glioma are not listed due to the potential identification of two patients with a rare diagnosis. The remaining three were diagnosed with either a non-malignant tumour or metastatic disease.

A total of 80 patient and carer interviews were conducted, of these, 30 were paired interviews and 50 were separate. Nine bereavement interviews were conducted after the patient had passed away. A summary of patient and carer interviews conducted at each time point is given in table five. Details of patient characteristics and all interviews conducted are shown in Table six.

Interview stage	T1	T2	T3	T4	Bereavement
Participants	22 (13 patients, 9 carers)	32 (18 patients, 14 carers)	27 (15 patients, 12 carers)	21 (12 patients, 9 carers)	9 carers
Total interviews Paired/ separate	16 (7 paired, 9 separate)	22 (9 paired, 13 separate)	21 (6 paired, 15 separate)	11 (3 paired, 8 separate)	9 single interviews
Participants not taken forward to next stage	10 (5 patients, 5 carers) (Non-glioma)	10 (4 patients, 6 carers)	5 (3 patients, 2 carers)	n/a	n/a
Newly recruited participants	n/a	20 (10 patients, 10 carers)	5 (3 patients, 2 carers) ¹⁹	none	n/a

Table 5: Summary of patient and carer interviews conducted

4.1 Time one (T1) – the period before a formal diagnosis is made

Thirteen patients and nine carers took part at time one, the period before a formal diagnosis was made, in a total of 16 interviews (seven paired and nine individual). Seven of these interviews were conducted with the patient and their main relative together. Six interviews were conducted separately; three with patients and three with

¹⁹ Participants recruited at this stage had previously refused to take part but agreed to be contacted again at a later date, at which time they consented to participate.

main relatives or carers. Three single interviews were conducted with patients without a complementary relative interview as their relative wasn't available for interview at this time. 14 interviews were conducted in participants' own homes and two were conducted in a side room on the hospital ward. Informed consent was gained from all participants before interviews commenced.

At this stage in their illness journey, participants had yet to receive the pathology report that would confirm to them whether or not they had a malignant brain tumour. What participants had been told by this point varied widely depending on their referral route. Patients may have been referred to the neuro-surgical team via their GP or via a physician from either another department within the hospital or a neighbouring district general hospital. In most cases, patients had been told that a 'mass' or 'tumour' had been found following a brain scan. All but two of the twelve patients had undergone surgery, either a biopsy or partial or complete resection of their tumour at the time of interview. Histology was awaited to determine the type and grade of the tumour. Eleven out of thirteen patients had been discharged home and were awaiting a follow-up appointment at the neuro-oncology clinic where they would learn the results of their pathology and thus a confirmed diagnosis. Of the thirteen patients interviewed at T1, five went on to receive a diagnosis other than a malignant glioma and were excluded from further participation in the study. One of these five had an indeterminate diagnosis at the time of discharge from the study. Of the remaining eight patients, six were diagnosed with a glioblastoma multiforme (GBM) WHO Grade 4; one was diagnosed with an anaplastic astrocytoma WHO grade 3 (AA3) and one was diagnosed with an anaplastic astrocytoma WHO grade 3 with signs of change.

4.2 Time two (T2) – Starting treatment

Eighteen patients and 14 carers took part in a total of 22 interviews at T2, the period after a formal diagnosis had been made and around the start of treatment (nine paired, 13 individual). Twenty participants (10 patients and 10 relatives) were newly recruited at this stage. Nine of the interviews were paired, conducted with a patient with a confirmed diagnosis of glioma and their main relative, in most cases a spouse. 10 interviews were conducted separately; five with patients and five with main relatives or carers. Three single interviews were conducted with patients where no relative was available. Twelve interviews (five paired, five separate and two single) were conducted with participants that hadn't been interviewed at time one. 21 interviews were conducted in participants' own homes and one in a quiet room in the radiotherapy department of the hospital. Informed consent was gained from all participants before interviews commenced.

At this stage in their illness journey, participants had attended the neuro-oncology clinic and had the bad news conveyed that they had a malignant glioma. Patients and their families were told at this consultation what their proposed treatment was likely to be. It was explained to them that although their tumour could be treated, it could not be cured. In some cases patients asked how long they were likely to live to which their consultants did not give an exact figure but suggested that it might be in the order of months rather than years in the case of high-grade gliomas. Prognosis for low-grade gliomas was even less clear. No contact had been made with participants for a period of at least one week after their confirmed diagnosis in order to give them a chance to process and come to terms with what they had been told. For those who had not been previously interviewed, contact was made as soon as possible after this. For those who had taken part in a previous interview, contact was made and an interview arranged around the time they were due to start radiotherapy. One participant with a low-grade

tumour did not have any treatment at this time. Three patients also began concomitant chemotherapy.

Second interviews tended to pick up from previous interviews, proceeding straight into the latest events whereas first interviews were used to 'set the scene'. The process was more familiar to people by this time.

4.3 Time three (T3) – Finishing treatment

Fifteen patients and 12 carers took part in 21 interviews at Time three, the period after radiotherapy had finished (six paired, 12 separate and three single interviews). Five participants (three patients and two relatives) were newly recruited at this time. Those with low-grade tumours did not have radiotherapy at the time of participation in the study. These participants were not interviewed at times two and three (unless it was their first interview) but were picked up again around six-eight months later at T4.

At this stage of the illness journey experience had begun to diversify with some patients relatively well and able to resume activities of daily living, whereas others were very unwell and required a great deal of help and support with professional input. Although initial treatment was over, recent advances in treatment protocol meant that one participant also had a second round of adjuvant chemotherapy.

4.4 Time four (T4) - Follow-up after approximately six months

Eleven patients and nine carers took part in a total of 11 interviews at T4, around six months after the time three interview. Three were paired, six separate and two single interviews were conducted where no carer was available.

At this stage a number of participants were very ill or had passed away. Others remained well and their illness did not dominate their lives. After a number of interviews, I had become familiar to participants and a relationship had been formed. One interview, in exceptional circumstances, was conducted at a 'Time Five', following on approximately two months after the Time four interview. In this case, the relative wished to take part in a further interview as her husband's condition made a marked deterioration. An ethical decision was made to depart from the original study design in order to do this (see Chapter 11 for discussion on a more flexible or fluid study design).

4.5 Bereavement

A total of nine bereavement interviews were conducted with relatives of glioma patients. There were three males and six females. Eight participants were partners of the deceased patient and one was a patient's father. Bereavement interviews were conducted around three months after the person with a glioma had passed away.

4.6 GP Interviews

Twenty GP interviews were conducted for 19 patients. For one patient, two GPs were interviewed who had been involved at different stages of the patient's illness. Telephone interviews were conducted with eight GPs and face to face interviews with the remaining twelve.

4.7 Other health, health-related and social care professional interviews

A total of 47 interviews were conducted with a broad range of health, health-related and social care professionals caring for people with a diagnosis of glioma. Please see

Appendix 12 for a full list of the professionals interviewed. Telephone interviews were conducted with two professionals and the remaining 45 were face to face.

Participant pseudonym	Carer pseudonym	Age at first interview	Diagnosis	Interviews conducted (T=time)	Paired/ separate patient/ carer interviews	Status
Bill	Wife Audrey	63	GBM	T2, T3, T4, T5 (carer only), Bereavement, GP	Paired	Deceased
William	Wife Shauna	64	GBM	T2, T3, T4, Bereavement, GP	Paired	Deceased
Mary	Husband Jim and daughter Ailsa	76	Anaplastic astrocytoma (AA) 3	T1, T2, Bereavement GP	Paired	Deceased
Andrew	Wife Sheila	45	GBM	T1 patient only, T2, T3, Bereavement, GP	Separate	Deceased
Winnie	Husband Norman	59	GBM	T1, T2, Bereavement, GP	Paired	Deceased
Jenny	Parents Bob and Diane	34	Not a glioma	T1 only	Individual patient and paired carer interview	Unknown
Hannah	No carer available	35	Not a glioma	T1 only	Individual	Unknown
David	No carer available	48	Brain stem glioma	T2, T3, T4, GP	Individual	Surviving
Sarah	Husband James	66	Not a glioma	T1 only	Separate	Unknown
Ann	Husband Oliver	66	Not a glioma	T1 only	Paired	Unknown
Sandra	Husband Stuart	47	Not a glioma	T1 only	Paired	Unknown
Sandy	Wife Julie and daughter Cara	47	GBM	T1, T2, Bereavement, GP	Separate	Deceased
Ewan	Father Harry	21	GBM	T3, T4, Bereavement, GP	Separate	Deceased
Henry	Wife Alice	65	GBM	T1, T2, T3, T4, GP	Paired	Surviving
Deirdre	No carer available	56	GBM	T1, T2, T3, GP	Individual	Deceased
Angus	No carer available	59	GBM	T2, GP	Individual	Deceased
Harriet	Husband Alistair	64	GBM	T2, T3, GP	Paired	Deceased
Adam	Wife Cindy	28	Astrocytoma 2/3	T2, T4, GP	Separate	Surviving
Malcolm	Wife Joan	43	Astrocytoma 3	T1, T2, T3, GP	Paired	Surviving
Wilson	Wife Angie	58	GBM	T2, T3, T4, Bereavement, GP	Separate	Deceased
Barbara	Husband John	45	Oligodendroglioma	T2, T4, GP	Separate	Surviving
Lois	Husband Steven	50	GBM	T3, GP	Separate	Surviving
Ian	Wife Sharon	46	GBM	T1 patient only, T2, T3, Bereavement, GP	Separate	Deceased
Ron	Wife Betty	64	GBM	T2, T3, T4 patient only, GP	Paired	Deceased
Robert	Wife Beth	36	GBM	T2, GP	Paired	Deceased
Christine	No carer available	37	Astrocytoma 2	T3, GP	Individual	Surviving

Table 6 – Participant and interview details

Chapter Five: The limbo before a formal diagnosis

This chapter illustrates the trauma of real-time experience of 16 patients and nine carers in addition to 13 patients and 12 carers²⁰ reflecting back on their experiences at a later date. Participants were keen to share the story of how they had reached their current crisis. These narratives set the scene for the interview, giving history and context, details about participants' lives that allowed the researcher to construct a picture of their lives as a whole. These diagnosis narratives were seldom repeated in subsequent interviews but were often touched upon or returned to in part, particularly when the journey to diagnosis had been especially difficult.

5.1 Dramatic versus gradual presentation

Many participants could remember with real clarity the distressing events that occurred leading to their call to NHS24; attendance at their GP; admittance to hospital; or other presentation to the health service that led to their diagnosis.

In many cases the symptoms appeared quite suddenly with loss of mobility, seizures or black outs and people contacted emergency services,

It felt like I had been drunk the way I was staggering all over the place. The leg was dragging. And... I phoned the doctor. And he thought it was just a slight stroke... but I was having terrible headaches. And, er.. So I had to get the doctor in again, and she er, sent me to <hospital> where they did a brain scan and they found there was a growth in the brain.

(William, 64 year old male, GBM, time two)

In some cases participants remembered the exact date when symptoms started,

²⁰ Those newly recruited at times two and three (see table five in chapter four)

It was on January 2nd 2007 and I was driving my wife, my daughter into [town] to go to a film and I started to feel sick. And, and then they yelled at me that I was going to be crashing into a car and I crashed into a car. And that was the first thing I knew about it.

(Wilson, 59 year old male, GBM, time two)

Relatives similarly had the initial incident etched on their memory,

Well, er, it was on the 19th of December I was at work and [patient] had a, a seizure sitting here.

(John, husband of Barbara, 45 year old female, low-grade glioma, time two)

For others it was more a gradual process where they eventually became overwhelmed by symptoms, or symptoms suddenly became more severe and they decided to seek medical attention,

Erm, well I was just having headaches. Erm, and they kind of came and went for a while. Er, I was just kind of, I started taking Anadin and stuff erm and they seemed to help. Er, but then eventually erm, eventually they kind of well, they were just pretty bad so I got an emergency appointment at er the hospital in [town].

(Ewan, 21 year old male with a GBM, time three)

Sandra described several frightening ‘funny turns’ before an MRI scan confirmed the presence of a tumour,

The little funny turns which were almost like, it felt to me, almost if I was having the start of a seizure. But never went into full seizure, never ever. Just a bit of a shuddering in my head and wanting to just be lying down. But never ever lost consciousness or anything like that. Just, you know, I was working. I was scared, I was very scared.

(Sandra, 46 year old female, suspected glioma, time one)

Another participant had experienced a few strange episodes which turned out to be seizures. On one occasion he realised his memory was badly affected, which prompted him to go to the GP,

I was checking my email and er, I realised that the, the password I was using, er, many times a day, I couldn't remember that for some minutes. And er, then erm, I decided to go to the doctor.
(Malcolm, 41 year old man, suspected glioma, time one)

Bill had headaches that he felt were out of the ordinary,

Sort of limping on the left side a bit... So it was only when the headaches started. I had about four nights where I was waking up in the morning my head was thumping, so I thought this is not right, cos I never get headaches like that.
(Bill, 63 year old male, GBM, time two)

Despite experiencing poor memory and beginning to have difficulty walking, it was only when these symptoms were combined with inordinately painful headaches that Bill decided to seek medical help.

Robert describes the build up to his diagnosis and how certain little things that happened only gained significance once his tumour had been discovered,

At the time I didn't realise that it was a seizure, I thought it was just like a wee faint or something. And likes a few times we were out driving and maybe driving along and I hit the kerb. I meant to press the brake, and pressing the accelerator. Ken, these are like wee things that just you never thought of. Ken, but it wasn't until after that [carer] was actually saying that a few times we thought, remember that time when were out in the pub, and you were standing there with your pint like, ready for drapping it, no drapping it but spilling it? Yeah, right enough. I remember that. Ken? There'll be other wee things tae but probably maybe didnae just pick up on them as such.
(Robert, 37 year old male, GBM, time two)

It was often with hindsight that symptoms explained away at the time became clear as indicators of the tumour all along. It was often carers who noticed variations in their loved ones' behaviour,

Sort of looking back now, I would say even when we went on holiday in July. We went to [country] for 2 weeks and [patient] basically lived in the room for 2 weeks and slept a lot. But I just maybe put that down to work.
(Julie, wife of Sandy, 47 year old, suspected glioma, time one)

Erm, well it's, with hindsight, you think well he wasn't doing as much in the summer as might have been. We didn't play as much mixed golf and he didn't cut the lawn as often as he used to. [...]It's only, with hindsight, you can start to think that oh right well, you know he wasn't just quite himself.

(Alice, wife of Henry, 65 year old, suspected glioma, time one)

It was when a sudden and marked unusual symptom appeared that alarm bells started ringing and carers encouraged their partners to seek help. Symptoms such as slurred speech or sudden weakness on one side came as a shock and people took prompt action to seek help.

Each of the cases above illustrates how exceptional symptoms led to seeking medical help whether or not they began gradually or suddenly. They generally could no longer be easily explained by more common ailments such as stress and combined with alarm to family members, prompted action to seek medical help.

5.1.1 Delays in reaching a diagnosis

When symptoms were gradual and non-specific, the period leading up to a diagnosis was, for some, comprised of confusion, waiting and uncertainty.

Some participants were very distressed at the long process of diagnosis and the clinical significance of diagnostic delay,

I don't blame anyone for the delay I sort of understood it really as a clinical thing but you just it's not, I've got to try and put it out of my mind that hopefully three months hasn't shortened my life span significantly.

(Hannah, 35 year old female, suspected glioma, time one)

In many cases, people were given a misdiagnosis before their brain tumour was detected. David was angry about this,

Well I suppose the main issue is [...] I feel that I have basically been misdiagnosed before coming here. [...] But I went to the doctor a few times. I, I started, I think it was about February this year...and I just felt he was no really taking on board this. I mean, I don't think at any point he considered a brain tumour, but I think that was what I kind of find frustrating about that.
(David, 48 year old man, brain stem glioma, time two)

The problems, but they were in hindsight, were seeing different doctors, the doctors not appreciating the seriousness, [patient] not putting over how serious it was. Erm, the complication of living in [town], his home sort of here, his parents, doctor in [town], register a doctor in [town], all the different parties. The weekend situation where you phone up NHS 24 and went off to [town] to see the on-call doctor. But no diagnosis. Erm, I think the doctors realising that when a young person comes to the surgery with something that [patient] was reporting, for a person whose never visited a doctor for years, that maybe there is something pretty serious here.
(Harry, father of Ewan, 21 year old male, GBM, time three)

Respondents commonly reported things moving slowly as investigations and tests were being done but began to move very quickly once an anomaly had been picked up on the scan,

Having said that, once I got my GP onto the [hospital] neurology, I can't fault it because it all happened within days. Just a few days and it was all done and dusted really.
(Sandra, 46 year old female, suspected glioma, time one)

Participants felt a sense of urgency and immediacy so that even a short period felt like a long wait. However, many participants also rationalised why they had to wait,

I keep, looking back now because you've got time to sort of reflect on things that have happened, I think you always want answers like that...immediately, and I understand now that that's no always been possible. You know, like you're waiting on results coming and you're saying why are they no coming up to see us ...but then you realise they've got a job of work to do and they're in surgery and then they've got other patients and they do get round everybody. But it's just, we want to know things immediately.
(Julie, wife of Sandy, 47 year old male, suspected glioma, time one)

5.2 Feeling better and euphoria after surgery

Although physical and cognitive symptoms were debilitating and the source of distress for respondents, many people experienced a recovery after biopsy or resection of their tumour,

Some of the things were a bit funny to begin with I was, before I went in, I was struggling to get enough on my fork, it was falling off you know. And subsequently I've found that, whereas one day I couldn't get out of the bath, I find it really easy now... In the hospital, the guy came round and he showed me how to get in the bath and try and get out of it and that wasn't very easy at all. And as a kind of joke thing, I can now turn the left hand tap off and on with my big toe.
(Henry, 65 year old male, suspected glioma, time one)

I was able to rattle off the things he'd asked me to remember no problem. Erm, just feel a helluva lot better, I dinnae feel so blocked in.
(Adam, 28 year old male, low-grade glioma, time two)

Sandra also found that despite problems immediately after surgery, her condition was also improving day after day,

Erm left leg didn't work particularly well at all even when I woke up. But it's getting better all the time. I am walking pretty well now and getting stronger all the time. And peripheral vision...it's improving all the time.
(Sandra, 46 year old female, suspected glioma, time one)

It was also possible that participants' road to recovery after surgery could be in part due to the type of tumour they have, such that subsequent diagnosis impacts on their experiences.

Participants expressed relief in the time immediately following surgery but before a confirmed diagnosis,

S: Completely buzzing. I was completely, I felt that, I felt good.
St: As I say, partly the drugs, partly the fact that you've been through it.
S: I think just a lot of relief and just a lot of euphoria at that stage actually, yeah.
(Sandra and Stuart, 46 year old female, suspected glioma, time one)

It's, it's marvelous what they can do...I just feel so blessed doll, I really do, I feel so blessed. [...] I honestly feel as if I've won the lottery. I do. To have come through and had a tumour removed. No amount of money would, could make me as happy as I feel the now.
(Deirdre, 56 year old female, suspected glioma, time one)

Henry explained why the relief was so immense after surgery,

Er, I felt really good, fit and pleased to be about. Because the night before it's quite funny, he explained in terms of a 10% chance of it going wrong. Which I suppose you could also take it as a 90% chance of going right. But you tend not to look at the 90% and it's the 10% that's worrying. [...] I must say, it's like a second chance.
(Henry, 65 year old male, suspected GBM, time one)

The fear and anxiety that built up for many before undergoing surgery meant that the period immediately after surgery was often a happier time for the patient themselves although not necessarily for relatives. Euphoria at this stage was complex and could have been related to relief of symptoms; relief to have survived the operation; lack of awareness of prognosis (and therefore an assumption they were possibly cured); or steroid effects.

5.3 Uncertainty waiting for formal diagnosis

Despite a sense of relief at feeling physically better after surgery, there was still, without exception, an immense amount of uncertainty to follow as people awaited confirmed diagnosis. Not knowing what could be wrong was very distressing,

I was scared, I was very scared. It made me feel there was something going on, you know. And I was thinking, was it my age? Was it, was it *panic attacks*? Was it my *heart*?
(Sandra, 46 year old female, suspected glioma, time one)

Participants became very emotionally distressed when considering what the future may hold, for example for Hannah and her young family,

I knew as soon as they knew that it was a tumour and [...] was possibly going to be high-grade and was a... going to mean a lot of treatment but more importantly it would probably mean (VERY DISTRESSED) you know a very uncertain future...
(Hannah, 35 year old female, suspected glioma, time one)

Uncertainty appeared to be related to lack of information in a large majority of cases, where information was sought to reduce anxiety,

His follow-up appointment is this Wednesday, which cannae come quick enough for me really. Erm, just til we find out the biopsy results, what type of tumour this is, what's the treatment gonna be for this one that's still there and just basically a whole load of questions that we need to ask on Wednesday.
(Julie, wife of Sandy, 47 year old man, suspected glioma, time one)

5.4 Limbo and emotional 'numbness'

In the time before formal diagnosis, participants appeared to experience a flattening of emotions, a kind of paralysis in terms of making sense of what was happening and being able to emotionally process it. The period of waiting was for many like a time of 'limbo', waiting for results and having no idea what course their illness journey would take,

No, no. Erm, but you're still a bit in limbo because until Wednesday comes, when we know the diagnosis and the sort of regime of the treatment. Because you can't make plans, you don't know what's involved.
(Alice, wife of Henry, 65 year old male, suspected glioma, time one)

People's lives were thrown upside down and into turmoil. They often put their lives on hold until they knew what was happening and could begin planning again,

And the sort of black cloud that hovers over you. So I know a bit, I don't know how you feel cos no one can say how someone else feels but I understand how worrying it can be and also how it's very difficult to get on with life and the ordinary things in life when you've got that hanging over you. Um and that's why you know the sooner that's dealt with and the better we know what we're dealing with and moving forward the better.

(Norman, husband of Winnie, 59 year old female, GBM, time one)

Being told that a tumour had been detected on a scan often left people in a state of emotional limbo, feeling numb and unable to think or feel anything,

And well to be quite honest, yir, you're stunned, you know. Er, I think they were gettin' worried because I had no reaction, you know, you just sit there.

(Ann, 66 year old female with suspected glioma, time one)

Well I can't really say how I feel because I don't know. [...] I'm feeling I'm going backwards. Um... I don't really feel anything really.

(Winnie, 59 year old female, suspected glioma, time one)

While participants were going through a crisis, they appeared to be numb to emotion and were unable to objectively evaluate what was happening. Looking back, people were aware of this effect,

I felt like, my head was in a pad of cotton wool.[...] Erm, but now I feel like the fog's lifted a wee bit.

(Sharon, wife of Ian, 46 year old male, GBM, time two)

So it was just all like a, I don't know, just a blur really.

(Sheila, wife of Andrew, bereavement)

There appeared to be a natural human resistance to the limbo period as participants waited for a confirmed diagnosis. Participants seemed to be keen to move things forward, partly to be able to gain more information about their diagnosis and partly to have a plan of action and sense of purpose and control, moving on from the freefall in the waiting period. However, the concept of moving forward was in tension with a

resistance to thinking about the future and what it might hold, leaving people in a terrible suspended position where they could not move in either way.

5.5 Receiving a formal diagnosis

The bad news of a confirmed diagnosis of glioma was shocking and distressing for participants,

I was horrified. I was really horrified.

(Sharon, wife of Ian, 46 year old male, GBM, time two)

He'd been told that it was an aggressive cancer and that he had to have erm, 6 weeks of chemotherapy, radiotherapy and chemotherapy at the same time, 5 days a week. Erm, and [husband] was telling me this on the phone and I was silent for the first time.

(Angie, wife of Wilson, 58 year old male, GBM, time two)

In many cases, participants had been told they had a brain tumour and so they were able to prepare themselves for the bad news,

We had been told before that it was a tumour. But they didn't know what kind of tumour it was. I was kind of half expecting...

(Mary, 76 year old female, AA3, time two)

For people who had experienced unusual and confusing symptoms, the detection of a brain tumour provided the solution they were looking for,

When they said that it was a tumour, I thought that explains the problem. And as often as no, that's, that's as important to me as anything.

(Sandy, 47 year old male with a GBM, time one)

However, regardless of expectation, the confirmation still came 'out of the blue',

Um we understood the diagnosis and we're obviously shocked by it. Although we rather expected it um from what we were being told um and that obviously sends you into a bit of a state of shock at first.

(Norman, husband of Winnie, 59 year old female, GBM, time two)

People found the diagnosis difficult to make sense of when the patient was previously fit and well, with no warning of illness and when it did not fit with people's expectations of illness,

It was just like really suddenly like, he's never been ill before

(Kerry, daughter of Sandy, 47 year old male, GBM, time two)

It's a shock. [...] For something to happen so out of the blue, you know, [patient]'s never ill.

(Sharon, wife of Ian, 46 year old male, GBM, time two)

5.6 Summary

Participants expressed a need to share their emotional and detailed diagnostic narratives in research interviews. For some, symptoms emerged gradually while for others very suddenly. Shock and distress were evident in all participants' accounts. There was a lasting impact on their perception of the time leading up to a diagnosis for those who experienced a complicated path. Dealing with physical and cognitive symptoms was also distressing for patients and there was a sense of relief and even euphoria for many in the period immediately following surgery as they began to feel physically better. However, participants were left with an overwhelming uncertainty as they awaited a formal diagnosis. Many participants were unable to fully describe the extent of the impact of the news that a brain tumour was suspected, leaving them numb and in a state of emotional limbo. When the confirmed diagnosis of glioma was given, a new wave of shock and distress overcame participants as they tried to make sense of the news.

Chapter Six: Coping and adjustment

This chapter reports the process of adjustment to living with a glioma, making sense of one's situation and trying to cope successfully with it.

Over time, the emotional 'numbness' that characterised the early period around diagnosis described in chapter five lessened and people were more able to talk about their illness. In the weeks and months immediately after diagnosis, patient and carer narratives emphasised how they were dealing with their diagnosis and coping with the emotional turmoil that went alongside it.

There were marked differences in approach to dealing with illness. For some, gaining and having information was central to coping and the pursuit of information became a coping strategy, a focus and form of control at a time of great helplessness. Themes of distress and the role of information (see chapter seven) were strongly linked to coping.

The following sections report on the main themes generated in relation to coping and adjustment across the illness journey.

6.1 Emotional reaction

Respondents reported high levels of distress, anxiety and worry. These feelings were associated with uncertainty as well as concern about the future and for family members; dealing with physical and cognitive symptoms and the emotional turmoil of diagnosis. As well as direct examples of distress, anxiety and worry - which are reported here - these themes are, like uncertainty, threaded throughout all aspects of people's experiences.

6.1.1 Distress, anxiety and worry

John described the distress his wife was feeling at the time of diagnosis and how they coped as a couple with it,

She was thinking, she was on the black side. She was saying, oh that's it, I'm, there's nae chance, ken, I'm going away. And I'm saying to myself, dinnae be silly, we have to look on the bright side of it.[...] I knew how she was, and that's I was mebbe trying to compensate for that.
(John, husband of Barbara, 44 year old female, low-grade glioma, time two)

Bill shared the emotional distress he experienced since becoming ill,

I'm quite an emotional person so that when people ask me how I'm doing I can't talk sometimes. You know. [...] I do think that you have this horrible feeling yourself this churning in your stomach and this horrible feeling that your life's never going to be the same again.
(Bill, 63 year old man, GBM, time two)

Robert described the effect that his diagnosis had on him,

Aye, I've noticed a bit of a change in myself like aye. And 9 times out of 10 something wouldn't bother me, I just ach, but aye, this is getting to me now, a wee bit.
(Robert, 37 year old male, GBM, time two)

Aspects of participants' illnesses were also very distressing to witness for family around them,

I think it's just like, probably seeing my dad upset. Just, I think, just his frustration cos he did everything for us so it's just like, seeing him upset because he cannae like help us.
(Kerry, daughter of Sandy, 47 year old male, GBM, time two)

The shock of being told a mass or tumour had been detected on a scan combined with fear of what that might mean for the future were evident. Feelings of distress, anxiety and worry were more evident at time two than at time one due to the emotional 'numbness' described in chapter five.

6.1.2 Distress over time

As people adopted more practical solutions to dealing with their illness on a day to day basis or were able to recover a level of normal function (see chapter eight), acute distress was less evident. However, it was clear that distress *did* endure over time and was present in every participant's account,

I don't like [patient] continually talking about it because it just brings everything back to me.
(*Shauna, wife of William, 64 year old male, GBM, time three*)

The worst thing for me is probably goin' to bed at night and thinkin' it was maybe the last time you're, you know, you're gonna wake up in the mornin'.
(*Andrew, 45 year old male, GBM, time three*)

Audrey, when I spoke with her in an extra interview, recalled how certain songs sometimes 'set her off' and she went through times of feeling okay and times of feeling overwhelmed with sadness,

I think erm, you go through different stages. I mean, when you get the diagnosis and everything its terrible and the pain of it. And then sometimes, mebbe in the evening, you sort, it floods over you how dreadful it all is and everything. And the sadness of it. He's getting worse all the time. And erm, gradually we're losing him
(*Audrey, wife of Bill, 63 year old male, GBM, time five*)

Emotional distress expressed in later interviews did sometimes relate to a particular issue such as physical or cognitive symptoms; practical problems; fear and uncertainty; and facing death, as well as a more generic worry or sadness.

6.1.3 'Fearing the worst'

It was evident that thoughts of death and dying were paramount in peoples' minds in the period where they did not know what the outcome of their illness would be,

Sheer and utter panic. And very, very stressful. I can't describe it any other way. There's obviously lots of morbid thoughts going through my head, you know. It's probably been the most difficult two weeks of my life.

[..]

Erm, but I'm still very, very nervous of it you know. I don't have the physical strength I don't think, the emotional strength to ask myself too many questions at this stage.

(Sandra, 46 year old female, suspected glioma, time one)

Just awfy, I'm just petrified. I just want to be back to normal.[..] I just got a bit o a shock when it's to dae with your brain and that ken. This was like, really scary stuff because it made me think mair aboot the kids and the wife like if I'm no gonna be here who's gonna watch them like eh?

(Ian, 46 year old male, suspected glioma, time one)

Relatives were also worried about losing their loved one,

Well all things go through your mind, you know. You, I don't know, you're inclined to think the worst. If you think the worst and the worst comes it's no such a great shock.

(Oliver, husband of Ann, 66 year old female, suspected glioma, time one)

Erm, well, I know that there's a great possibility that I'm going to *lose* her. Erm, sooner rather than later, you know. I feel that but I'm trying not to let that show, you know.

(James, husband of Sarah, 66 year old female, suspected glioma, time one)

However, the overwhelming fear expressed in the earlier interviews did ease for some as they adjusted to their illness,

I think we're beginning to be, well I am, less frightened of it. [..] But it doesn't go away.

(Alice, wife of Henry, 65 year old male, GBM, time three)

6.1.4 Anger and frustration

One form of distress that was less explicit among participants was feelings of anger and frustration. Problems dealing with anger were most evident in the case of Sandy, who struggled with very strong feelings,

Erm, the not well bit is just a blasted nuisance. You know, I just, I hate being unwell. I've suffered with these migraine headaches for years and years and I just, absolutely detest no being right.

For this participant as well as others, the source of the anger is related to feelings of lack of control, being cheated and a desire for things to be the way they were,

Erm, and just get back to normal. Cos this is murder. And I should be oot on the stot, racing aboot all over the place, cos that's the way I normally kind of operate. . Erm, I'm in the habit of being in control and suddenly your control is doon a wall. And that's a bit o a nuisance.
(Sandy, 46 year old male, suspected GBM, time one)

A feeling of being cheated was common,

I'm going to sit here thinking, well there's things left to do and stuff like that. But you just have to come to terms with that.
(David, 48 year old male, brain stem glioma, time four)

Carers also had to deal with anger from patients,

It made him very angry. And, so I then got the brunt of his anger and that's hard.
(Angie, wife of Wilson, 58 year old male, time three)

In later interviews with Wilson, it became clear that anger was preventing him from opening up and talking to me in earlier interviews.

Anger was also evident in the non-verbal cues from participants. There were not many cases where anger was expressed, but this was possibly because participants did not

want to share it with me and preferred to show a façade of dealing successfully with their illness.

6.2 Moving forward and coming to terms with it

People appeared to go through a process of immediate shock followed by taking on board the new information and trying to accept it and move forward from the limbo experienced in the early part of the illness,

I think he is more relaxed with living with this because it is not going to go away. And, but it is a very difficult thing to do. And it's moving on.

(Alice, wife of Henry, 65 year old male, GBM, time four)

However, participants appeared to go through a very fast process of trying to come to terms with what was happening (or at least talking in this way) even before they had a confirmed diagnosis,

The thing is you've just got to accept it and that's it. If you don't accept it, if you cry, you lie down to it, if you laugh you're OK. It is quite hard the first few days speakin' about and that, but after a while it's..

(Ann, 66 year old female, suspected glioma, time one)

I kept thinking, how's he managing to take that but it was just I was like, gobsmacked at first. But you know, I think it's just initial, you know, totally unexpected. But you just get on wi it now.

(Julie, wife of Sandy, 46 year old male, suspected glioma, time one)

Many participants felt they had no choice but to 'get on with it',

So it's very much just a case o, oh well, it's got chunked at you, you've just got to catch it and run with it.

(Sandy, 46 year old male, suspected glioma, time one)

What am I supposed to do? Nothing you can do about it. It's there, you know, they can't wave a magic wand.

(Sarah, 66 year old female, suspected glioma, time one)

Some people felt that there was an element of fate in what has happened,

It if had to be it'd be aye.

(Mary, 76 year old female, anaplastic astrocytoma, time one)

Participants were able to reflect on the change in them over time in later interviews,

I know that early on, just after the operation, I couldn't have spoken about some of these things. I couldn't, but, but you go through it. It was very soon after the treatment finished when I got through that.

(Henry, 64 year old male, GBM, time three)

Basically what I was told when I first, to I got my brain tumour, ken, I was stunned. But I am alright, I wasnae at the time like, but I'm alright noo like.

(Ron, 64 year old male, GBM, time four)

Dealing with the potential diagnosis and trying to accept it appeared to be harder for some participants than others. Lois did not feel she had moved on from when she was first given the diagnosis,

I: Do you feel you've had a chance to come to terms with it?

L: I have had a chance, but I don't think I've took it. I think when I start feeling it then I'll need to start thinking right. But as long as I feel the way I'm feeling, I'll no accept it.

(Lois, 50 year old female, GBM, time three)

Christine explained that you can never accept it 100% and just live with it and carry on until things changed and you have to re-orientate and assimilate again,

So, it'll come back and I know it will so I'm just gonna live with it like this until, until it does start to come back. And then I'll see what I'll do with it then. [...] I just live with it.

(Christine, 37 year old with a low-grade glioma, time three)

Acceptance appeared to come later for carers than it did for the patient themselves, often when they realised that their loved one was not going to get better and had to 'let them go'. For some, it was only looking back after their loved one had died that they saw the block they put up in coming to terms with their loss (see chapter nine).

6.3 Coping strategies

People adopted a number of different approaches to help them deal with the seriousness of their diagnosis. Gradually, participants were more able to talk about a number of strategies used to cope successfully and make sense of what was happening, a selection of which are reported in this section.

6.3.1 Taking it as it comes

Coming to terms with and taking the situation on board was related to taking one day at a time and dealing with each new thing as it happened, a common approach to dealing with uncertainty. This was a strong theme emergent from people's accounts.

In early interviews, participants talked about the 'project' they faced to try and deal with what was happening, suggesting that in talking in this way, they could actively try and cope with the despair they felt,

OK that's how things are, now it would be, the project is just to deal with every day as it comes and just be grateful for every day that [patient] is here. And make the best of the day really, just take it one hour at a time or one day at a time.

(Joan, wife of Malcolm, 41 year old male, suspected glioma, time one)

Thinking too far ahead was overwhelming,

The best way to cope wi anything like this is, you do not look ahead, you just cope wi each day. [...] Erm, cos, you cannae say, oh if that happens, if that, you know, if this happens and the next thing because then I think your mind just goes haywire.

(Julie, wife of Sandy, 47 male, suspected glioma, time one)

However, in practice, it was not easy,

We just have to take every day as it comes. It's just the not knowing I think.[]I mean, you've just got to get away from it and just get on with everything, eh? Just keep things ticking along. [Distressed] I'm no much good at this am I?

(Sheila, wife of Andrew, 45 year old male, GBM, time two)

Over time, accounts became more convincing as people had overcome the initial shock of their diagnosis and had time to adjust,

But you know, this is what happens... you just take it as it comes. You get over, you get over these things you know.

(Andrew, 45 year old male, GBM, time two)

The longer it goes on the more you come to terms with it. And er, I don't think I necessarily feel different about it, it's just a matter of [...], this word I have used, 'realistic', 'suck it and see'.

(David, 48 year old male, brain stem glioma, time three)

However, there was less evidence of the theme of taking it as it comes in later interviews (times three and four). Participants were perhaps more likely to have accommodated to their new circumstances at this stage and the concept of taking it as it comes evolved into a focus on the here and now. People talked more about making the most of each day and living in the moment.

6.3.2 Living in the moment

As part of a changing philosophy in life is the notion of staying in the moment; living with what you have and making the most of it. This philosophy helped minimise stress,

That's the power of now. Erm, yes I mean it's a way of dealing with stress. So, yes, that's still there. Erm, and it's also part of trying to think the thing away.

(Wilson, 58 year old male, GBM, time four)

Living in the moment helped people take the focus away from an uncertain future and make the most of the time they had together,

You do appreciate your time more than ever. Cos before you're always saying oh we're looking for this to be happening in the future but we're not because you don't want your life to be going on too far in case that's your life ebbing away.

(Audrey, wife of Bill, 63 year old, GBM, time three)

M: I'm trying to stay in the today life. And that er, I think is helping me.

J: Mindful living

(Malcolm and Joan, 41 year old male, AA3, time three)

6.3.3 Staying positive

Positive thinking in the struggle to come to terms with what was happening was another strong theme. People presented themselves as staying positive and having a fighting spirit in the face of difficult circumstances,

If you can stay positive that's always, if anything, a good thing.

(Stuart, husband of Sandra, 46 year old female, suspected glioma, time one)

It was important for some participants to surround themselves with people with a positive attitude,

I had *good positive* visits from friends who, I think if I would advise, I would just be very selective about who you have round about you.

(Sandra, 46 year old female, suspected glioma, time one)

But then as you say, everybody's got a different attitude towards things. And when I went to get my erm, my radiotherapy there was a waiting room, or there was the café, which I'm sure you know. And they put me in the waiting room once and I won't, I wouldn't go back because it was full of older people who didn't have the same attitude as me. And I just decided that no, that's not what I want to sit and listen to.

(Christine, 37 year old female, low-grade glioma, time three)

Carers were also keen to protect their loved ones from negativity,

I said now [sister], you're not going if you're gonna go in there and cry or you know, be upset because I know that she has been. [...] I think he felt that everybody thought he was on death's door you know. [...] God he says, everybody's got me as though I'm not gonna be here next week.

(Julie, wife of Sandy, 47 year old man, suspected glioma, time one)

Being positive and having the 'right attitude' was associated with ultimate survival,

One person at 60 could go under and one person at 60 could survive. Depending on their mental attitude. And positivity, which is true.

(Ron, 64 year old male, GBM, time two)

Carers were able to gain strength more easily when the patient themselves showed a positive attitude towards their situation and were physically well,

And I would find that more difficult if he wasn't so positive, but he is, so that makes it easier for me.

(Angie, wife of Wilson, 58 year old male, GBM, time two)

But I am thinking maybe I am just maybe comfort with him just now because he is here. And er, he is looking well. So that is making me feel positive about the whole thing.

(Sheila, wife of Andrew, 45 year old male, GBM, time two)

In some cases, patients were aware of the importance of being seen to cope in order to help those around them do the same,

Because it just, it makes it easier for my family as well if I accept it like this cos if I didn't then it would bring them really, quite far down. So, I just have the attitude to keep going.

(Christine, 37 year old female, low-grade glioma, time three)

At times, for carers too, it was frustrating to present oneself as positive at all times,

It's quite a responsibility to be told to be positive all the time, and optimistic. And, and people, you know, in a way they are saying, 'don't bother me with the details cos I can't cope with it'.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

The theme of positivity endured over time. Once a glioma had been diagnosed and people's agenda shifted, they remained positive about other aspects of their circumstances such as physical recovery and getting back to their normal life.

6.3.4 Fighting spirit

At time one there were not many accounts of 'fighting' illness. It is likely that at this stage people did not know what they were fighting against or were too shocked to mobilise their resources to fight. It is only once their diagnosis of glioma was confirmed that people started to make use of the repertoire around the 'battle with cancer',

I'm just going to... Get on with my life. My life didn't stop because I have a brain tumour. [...] I'm not giving in to it. I am definitely *not* gonna sit back, turn my head.

(William, 64 year old male, GBM, time two)

This participant took on the persona of the fighter in this account despite a deteriorating condition, a more morally acceptable position than the perceived passive or weak person who gives in to their illness. Similar fighting talk was evident elsewhere in the data,

You've got to hae this, 'I'm gonna beat this, it's no gonna beat me'. Ken, I dinnae like anything to beat me, I'm no gonna let that beat me.

(Ian, 46 year old male, GBM, time three)

For many, it was a case of 'knowledge is power'.

If you don't know your enemy it's very difficult to visualise how you can attack it. [] Erm, and so long as I can feel positive and to turn it enough that I'm gonna beat it, the better. Erm, OK, I mean, I don't like being beaten erm, and I'm going to do my damndest to make sure that this doesn't. Alright?

(Wilson, 58 year old male, GBM, time two)

There was less evidence of fighting talk in the later interviews conducted with participants, particularly in cases where the patient has been unwell or had a recurrence of their tumour. Thoughts at this time turn to more 'magical thinking' – hoping that everything would be okay,

It's hoping and praying that it will continue that way.

(Harry, father of Ewan, 21 year old male, GBM, time four)

If it is, so be it, but I am going to try my damndest to make sure that isn't the case. I think I have always thought that if you can, you should be able to think things away. I'm a firm believer that it does work.

(Wilson, 58 year old male, GBM, time four)

6.3.5 Distraction and action

Participants were keen to take action with radical treatment as soon as possible so that something was being done to prolong their life,

I think from a psychological perspective from my point of view to feel that we're doing everything possible to try and keep this thing at bay for as long as possible. [...] At the end of the day I will go through anything in the short term to try and improve the long term because that's all I care about.

(Hannah, 35 year old female, suspected glioma, time one)

Distraction was also useful at the time people were waiting for a confirmed diagnosis to take people's minds off their fears,

We kept ourselves busy rather than sitting in here sort of thinking, you know. It's something that has to happen so you know, you're best keeping busy.

(Stuart, husband of Sandra, 46 year old female, suspected glioma, time one)

Distraction came to the fore again when people had completed treatment and were waiting for follow-up scans or dealing with uncertainty regarding tumour recurrence,

I try not to let it kind of take over my life you know, basically. [...] I think, well not necessarily not thinking about it but doing things to take my mind off it. And not kind of dwelling on it, I think is quite important cos otherwise it could just get you really down.

(Ewan, 21 year old male, GBM, time three)

Getting the dog was partly, I mean I think partly to help as well. [...] I get out for regular walks and everything. [...] And I think that's helped because it, it's just something there all the time to keep me active and occupied and busy and something to look after and so on.

(Harry, father of Ewan, 21 year old male, GBM, time four)

Keeping busy, such as returning to work, organising affairs or seeing friends was commonly considered a means of 'taking your mind off it' and helping to cope,

And we are just busy trying to focus ourselves and to de-clutter and the background bits so that we can make a list of things that we want to do and go and do them. [...] And it's moving on.

(Alice, wife of Henry, 65 year old male, GBM, time four)

So they came home and then what do they do? Worry about it. See, [patient] didn't have time to do that. He had enough going on, and enough things going on, erm, to, you know, well just keep him focused. And take, I suppose, take his mind off it.

(Angie, wife of Wilson, 58 year old male, GBM, time four)

6.3.6 Comparison with others

By considering themselves in a more favourable position to people less fortunate, participants were able to better cope with the seriousness of the illness,

And I dare say that there may be people worse off than me.

(Mary, 76 year old female, suspected glioma, time one)

And [patient] was quite fortunate that they could take it away. You know, there's folk who's had but they can't operate because it's in a bad place. .

(Oliver, husband of Ann, 66 year old female, suspected glioma, time one)

An active adjustment in people's thought processes is evident,

Erm. As I say I'm a fairly self contained person. I mean I'm no in a situation like, I mean, I think for somebody, like if I had a wife and kids, this would be a totally devastating position.

Erm, so I really don't know if that makes it any easier in a sense *but* again, there is lots of people out there in worse condition than I am. And as I say it's just a matter of thinking in accordance to come to terms with your own position.

(David, 48 year old male, brain stem glioma, time two)

For some, comparison with others and a positive appraisal is part of an existential

reflection on their life as they face it coming to an end,

And the I'll listen to the radio during the night some times you think, you hear some horrible things happening in Africa and you think well I've been lucky you know. Na I mean it's good because I've had quite a hard life you know I'm one of a big family and we were really poor and things have got better after that once I met <carer> and got married. (Distressed) I've had a I've had a really good time.

(Bill, 63 year old male, GBM, time three)

However, on occasion, participants compared themselves negatively with others and

this served to increase their anxiety,

I met a guy in the ambulance one day and he had er, cancer 25 years ago. And that's his come back in January, he's got a massive tumour in his back. And he's been telt basically there's no really much they can dae. I was getting myself upset because I was thinking, well that could be me, that could be me.

(Ian, 46 year old male, GBM, time three)

There is just a wee tinge of jealousy comes over you. When you see that and you think oh you know, they're so fortunate to be able to do that eh? And look after their grandchildren.

(Audrey, wife of Bill, 63 year old male, GBM, time four)

6.3.7 Influence of past experiences

Many people had already been through life altering events in the past such as accidents and the death of loved ones that changed their way of thinking,

O: See, we went er, about 10 year ago, we were in a RT accident. And it's er, it changes your life altogether, you know.

A: It changed our attitude altogether. You get your priorities right, what's important in life.

(Ann and Oliver, 66 year old female, suspected glioma and her husband, time one)

Angie describes the effect of nursing her parents through cancer,

I'm much more erm, philosophical, I'm more prepared and I think stronger actually. I really do, definitely.

(Angie, wife of Wilson, 58 year old male with a GBM, time two)

As time passes, Angie maintains her recollection of the strong influence living with cancer can have,

Now the very first time that happens, yeah, that's, that's a defining moment. But then, from then onwards it's terrible, but you do, you learn to live with it.

(Angie, wife of Wilson, 58 year old male, GBM, time four)

Shauna felt her experience working with older people helped her to deal with caring for her husband as his needs increased,

Sometimes I think, I would've fell to pieces. But I have watched, no going through brain tumours and that, but I have watched elderly people go through other illnesses and that.

(Shauna, wife of William, 64 year old male, GBM, time four)

6.3.8 Denial and disavowal

Participants appeared to shift the focus of their thoughts away from their illness when it was too difficult to deal with,

I: What were your thoughts about that then, about what was wrong with you?

W: Disbelief. Nothing's wrong with me.

I: And is that how you feel now as well?

W: I believe that if I can convince myself that is the situation, that will help make my, to make myself better. Erm, cos I think that if I can will myself to kill the bloody thing that will help. Erm, so life goes on. [...] Erm, to deny it's there, well not to deny it's there but to deny that it's actually gonna have a negative effect.

(Wilson, 58 year old male, GBM, time two)

Wilson chose not to attend to what was expected to happen to him and took his focus elsewhere in order to cope. His wife Angie was happy to collude with this and did not admit to herself while her husband was alive that he was dying. It was only with hindsight that she could see how they had ignored the serious facts of Wilson's illness,

I really wasn't going that route. I was focusing on the living and the quality of living and trying to make it as positive as possible. I think you do, I think you protect yourself, you put something round you. And you just focus.

(Angie, wife of Wilson, bereavement)

Andrew was happy to go along with his wife's disavowal to protect her from the painful reality,

Just because [wife] doesnae want to hear any more of that because she just wants everything to be fine y'know. And I think em, what I don't want is somebody else coming and saying it is no, well, it's no looking that great.

(Andrew, 45 year old male, GBM, time two)

Others focused on feeling physically well to help them shift their thoughts away from the reality of their illness,

Sometimes I think it's not true because I feel that good. And I dinnae want it to be true. I think for me because, because I'm that good I just keep going on as normal until I really do feel no well. And then I can start changing.

(Lois, 50 year old female, GBM, time two)

Disavowal, by its very definition, was not always apparent. It is only with time that the use of this strategy became clear in many cases. A discussion about taking part in research interviews gave an insight into the use of disavowal and how it served to help people function in everyday life without thinking about their situation, otherwise they would be overwhelmingly distressed all the time,

I, I think that we have our chats with you, I mean, they are all very nice but it wakens it up again. And it relives it all again and because I am very good at, well trying to get on with things. And trying to be, well I'm trying very hard to be as normal as we can, which is easier for me than it is for [patient].

(Alice, wife of Henry, 65 year old male, GBM, time three)

Sheila, who employed a kind of blocking in order to deal with her situation while enduring the crisis, was able to reflect only after her husband Andrew had passed away. She has some regret about this approach to dealing with what was happening and not talking about what they were going through with her husband, who took a different approach,

Sometimes I wish to myself that it was pointed out to me that I never let him speak about it. But it's no that I said to him, you can't, I just always said, oh no, we'll get better, we'll get, do you know what I mean? I think, if I accepted it then we would never have got through it. I just hoped all the time. [...] Even right to the very last minute, I was still saying 'no, no, no, we'll get through this'. But, inside I knew, do you know what I mean?

(Sheila, wife of Andrew, bereavement)

Similarly, Sharon ignored her gut feeling that her husband would not survive in order to maintain hope,

Cos I think I had that in my head from about sort of, March/April anyway. I kind of knew in my gut, that he was nae gonna survive it. But I didnae want to be negative either, you know. You always have to have hope of some kind.

(Sharon, wife of Ian, bereavement)

Shauna was aware that William knew ‘within himself’ that he would not recover. Interestingly, Shauna was very quiet in early interviews conducted but gradually gained confidence in sharing her experiences,

Even if he had to get my nephew to take him down earlier, he was still going on holiday to [town]. I just kept saying to him, right [patient], right. I knew he was nae but I think he knew within himself he was nae but. I thought, if that keeps him going well, just leave him.
(*Shauna, wife of William, 64 year old patient, GBM, bereavement*)

In this way, bereavement interviews were illuminating as participants were able to vocalise the thoughts and feelings they had previously been internalising, giving access to more private accounts.

6.4 Hope

As participants awaited a confirmed diagnosis, hope was related to wishing that all would be ‘okay’ and that treatment would be successful. Hope took the form of positive thinking as described in section 6.3.3, as well as a want, desire or faith in a good outcome. Hope was resilient and furthermore, hope appeared to be used as an important coping mechanism.

Having something to hope for was important to participants,

And I think just to see light at the end of the tunnel.
(*Ailsa, daughter of Mary, 76 year old female, suspected glioma, time one*)

Before confirmed diagnosis, participants hoped that their tumour would turn out to be benign,

You know, I've been praying myself. (laughs) Just that everything will, what's gonna be is gonna be, but hopefully it will be a positive outcome for us all.

(Julie, wife of Sandy, 47 year old male, suspected glioma, time one)

Hope was adjusted as new knowledge was gained,

I can only I think be positive and hope [...] that I'll be someone who flexes that rule in the right way and lives, I suppose you know you just bargain with yourself and again I've had to change the goal posts in that that end.

(Hannah, 35 year old female, suspected glioma, time one)

6.4.1 Shifting hope

As time progressed, participants' hopes changed. With a confirmed diagnosis, they could no longer hope for a benign tumour, but instead hoped for different things, such as a period of stable disease where life could get back to normal,

And I am really looking forward to the day that he will be able to drive again and go back to work. That would be just fantastic. So that is what I am sort of, hanging onto now.

(Sheila, wife of Andrew, 45 year old male, GBM, time two)

If I get the use of ma erm back again and I get off steroids and I get the use of my leg muscles again, you know. [...] And just thank my lucky stars I am still here. Cos even if I am just sitting here doing what I am doing, it's er, it's great.

(Ron, 64 year old male, GBM, time four)

Hoping that the tumour stayed away was another common concern for people further on in their illness experience, as Adam says,

So I just hope that it doesnae start growing again.

(Adam, 28 year old male, AA2, time two)

Adam talked about his hope for the future now that he was freed from the debilitating symptoms of seizures following surgery, and hoped they would stay away. However,

the issues were different for people with low-grade gliomas, who did not face the same immediate threat to life as those with high-grade tumours.

Hope was derived from patients feeling physically well, having a good recovery and treatment,

And when I went to see her after the operation, I was expecting to see her on drugs and bits and pieces, but she had two wee drips going and she was sitting up, quite happy. Which amazed me. It's no real as far as I can see. So you're saying to yourself, can they beat this thing?
(Steven, husband of Lois, 50 year old female, GBM, time three)

If the treatment starts to fail and things don't go very well, I'll start to lie down. You know, as long as you feel alright, you get chemo, you always have a chance of recovery.
(Angus, 59 year old male, GBM, time two)

Over time, people gained further knowledge of their disease and prognosis. Rather than face helplessness and hopelessness, people sought and found hope in even the most difficult situations,

Then we can just hope, we'll still hope anyway, it doesn't make any difference as far as that goes.
(Andrew, 45 year old male, GBM, time two)

And that even in the hardest times um we'll be comforted, there'll be something, it's all not negative.
(Audrey, wife of 63 year old male, GBM, time three)

One carer described his struggle with hope and realism in the face of uncertainty,

Is it just a question of hoping that he might be cured or is that a false hope? We just don't know [...] I'm hanging onto some hope that it won't happen. Or that he'll be far enough away that he can get back to a normal life for a period of time.
(Harry, father of Ewan, 21 year old male, GBM, time three)

This participant was also hoping for a miracle and was aware that this may be an unrealistic hope or 'magical thinking' - he may be engaged in disavowal - but it somehow made it easier to cope. He also appeared to be in the process of adjusting his hopes to something more realistic such as a period of stability.

6.4.2 No hope

In few cases, people were not able to find hope. For example, Ewan is despondent about what the future holds,

Well, erm, I'll probably be dead before I either finish the degree or get a job, you know, to use it. So it kind of seems a bit futile to go back.
(*Ewan, 21 year old male, GBM, time four*)

When Lois was asked about hope she replied that she had none,

The minute they took my sister away, nah. I just take life as it comes now.
(*Lois, 50 year old female, GBM, time three*)

Julie also felt they didn't have the chance to hope as her husband's disease was so devastating right from the beginning with no time for respite or to adjust to what was happening,

I mean, from basically the diagnosis in the middle of October, it was not even 12 weeks. And that's unbelievable. You know, just even to come to terms with getting told. And every time he seemed to go to the hospital, he got more bad news and more bad news, there never seemed to be any positive.
(*Julie, wife of Sandy, bereavement*)

6.4.3 Realistic hope

Patients and carers were aware of the role hope had to play and were cautious of being overly optimistic and the effect this could have in the long term if their hopes were not realised,

I don't know if I'm being overly optimistic, I just think well, we're OK the now so we'll just keep going, ken.

(John, husband of Barbara, 45 year old female, oligodendroglioma, time two)

In some cases, there was a difference between participants in terms of whether they wished to be given 'false hope' and wanted to be reassured,

B: I just feel people should nae say stuff like that.

R: But they have to, that's their job. They cannae gie you false er, hope.

B: No. No, but they could blur the edges a bit. It's kinder.

(Ron and Betty, 64 year old male, GBM, time three)

6.5 Social and emotional support

Social and emotional support were very important for patients throughout their illness.

6.5.1 Support from family and friends

During the period before a confirmed diagnosis was made, support from family and friends was considered vital,

It must be terrible for somebody that hasnae got er, family to support them.

(Ann, 66 year old female, suspected glioma, time one)

Partners and close relatives were an important source of support,

Oh definitely. Yeah, I mean.... I mean if I never had her I'd be, really be struggling.
(Andrew, 45 year old male, suspected glioma, time one)

Over time, both patients and their carers continued to value and relied upon social and emotional support from those around them as a source of strength and positivity,

I, I couldn't imagine doing this without my children. Erm, they have been fantastic, erm, and I just, I don't know, I, I am, it's making me more positive, more determined.
(Angie, wife of Wilson, 58 year old male, GBM, time two)

Having someone with you for support upon learning a diagnosis was also important,

I mean I was lucky I had him there all day wi me. To have sat there all day even yourself and then nobody comes and then somebody comes trotting in and tells you it like that is nae very nice.
(Barbara, 45 year old female, oligodendroglioma, time two)

However, social and emotional support was not always valued by everyone or seen as necessary,

[Very distressed] They make me angry. And I'd rather they didnae. I ken they're trying to be helpful. But in ma opinion they're not being helpful.
(Mary, 76 year old female, AA3, time two)

So it's as if like, as if your life is getting invaded. [...] We've got a close family but you know, none of the kind of family that you never see each other. But the minute something happens everybody's there. Like ants. But it's like as if everybody's taking over.
(Robert, 36 year old male, GBM, time two)

6.5.2 Peer support

Interactions with other patients and the perceived value of this were identified as an issue during the treatment period and beyond. Perhaps participants were more ready to hear other people's stories once they had some time to make sense of their own. In addition, in practical terms, it was more likely that patients were meeting more people when they were attending the hospital for treatment. At the time of surgery, the majority of patients were focused on themselves and their families although there were some cases of talking to people on the ward and forging friendships. Carers were more likely to talk to others by extension if the patient had encountered them.

For some, gaining peer support from other people in a similar situation was valued,

When I went into the clinic, I hear, I heard this voice saying, [patient], and it was the woman in the next bed to me in the [hospital]. And that was lovely, that was lovely and we put our arms round each other and traded stories and that.

(Deirdre, 56 year old female, GBM, time three)

There's a man that was in the same time as I was in the [hospital], he was getting treatment the same time that I was. And we got speaking, er, we got quite friendly. And er, my wife spoke to his wife once or twice, didn't you? And er, er, you are supporting each other, it's that way. [...]

(William, 64 year old male, GBM, time three)

We went to, it was like a young person's cancer conference type thing and it was good. Nice to meet some other people and things like, in the same situation.

(Ewan, 21 year old male, GBM, time four)

As illustrated in relation to staying positive, some patients did not want to be associated with other people with cancer and actively distanced themselves from peers.

6.5.3 Professional support

Support from health professionals was reassuring and a comfort to people and was valued immensely,

When she saw me in the outpatients and saw me in the cancer centre [...] she always came across and spoke, very pleasant. And that's a good thing because erm, although my wife was with me, you always feel a wee bit isolated on your own.

(Angus, 59 year old male, GBM, time two)

H: [Nurse] is fantastic. You can speak to her usually and she always helps if it is needed.

A: She just says the right thing at the right time. And she is just supportive. And just easy to get to and use. And you don't feel you are imposing cos she is a very busy person at all. And she has time for everybody. I think it is world class, the service at the [hospital].

(Henry and Alice, 65 year old male, GBM, time four)

A few participants had made use of additional support services which aim to provide information and support to people going through the cancer experience. This service was valued by those who used it,

So [patient] could ask questions because as I say there's things he wants to know. And she was very helpful as well and very positive as well about the whole thing. That was very helpful.

(Sheila, wife of Andrew, 45 year old male, GBM, time two)

While the medical side of things was often reported as going smoothly, it was in the area of support that carers went lacking,

OK, the medical profession can cope with the, you know, dispensing drugs and all the rest of it, but I needed to understand what the hell was going on. Do you know what I mean? And obviously I figured it out for myself. But a few, 2 or 3 months down the line, by that time I was exhausted.

(Sharon, wife of Ian, bereavement)

Not everyone expressed the need for additional emotional support,

I just feel that erm, er, that sometimes, erm, if you don't need the emotional support then I don't think you need to have these people coming.
(Audrey, wife of Bill, bereavement)

However, it is worth noting that at the time, Audrey valued the support from the palliative care nurse specialist to be able to keep Bill at home.

It is also important to consider that having the support of a small number of key individuals is sufficient and sometimes it is a case of 'too many cooks spoil the broth',

She wasn't a key element in his health care or looking after us, but she was very helpful. And [son] wasn't that comfortable with [additional support]. So, you know, I don't know. He had plenty of attention and didn't really need [additional support] to do anything extra.
(Harry, father of Ewan, 21 year old, GBM, bereavement)

6.6 Carers' concerns

In the early interviews, relatives were very much focused on the patients' needs. There was less talk about the difficulties experienced in their own role (possibly because there were few at this stage), although those interviewed separately were perhaps more likely to raise some of these issues (a phenomenon which stands even in the later interviews). As I was able to build a relationship with carers over time, some more personal and private concerns arose.

6.6.1 Carers' skills

The issue of caring skills was not raised in the earlier interviews. At this time, patients had frequent contact with medical and other health professionals and were often relatively well. The issue of having adequate skills to care for loved ones became a more

pertinent issue further in the illness journey when patient care was often transferred to the community after initial treatment was finished.

Participants often did not feel skilled at caring and preferred to leave it to the professionals,

I'm not, I'm not a nurse, you know. I'm not very good from that point of view. [...]I think that would be the time when one would call on the [hospice] nurses because they know what they are doing.

(Angie, wife of Wilson, 58 year old male, GBM, time three)

Distinctive issues such as cognitive deficit and personality change were perceived as more difficult for carers to deal with than physical symptoms,

You know, I mean if he was in his bed, being sick, I could do whatever, take things up and down to him. It would nae matter. But this personality change is much harder to cope with, you know.

(Sharon, wife of Ian, 46 year old male, GBM, time three)

Carers did not always know what to do in the case of an emergency as there was no protocol available to them,

I had no idea whom to call. I was absolutely just, I couldn't, the only number I had was, we had, was [nurse]. And she is only there in office hours.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

On the other hand, carers had often learned more about the illness and their confidence had grown,

When I started looking after him myself, which was December when I started doing the night care. The first night, I thought, how am I going to manage? Sort of, almost felt physically sick then. But it was great and I was really getting good at it, although I say it myself.

(Audrey, wife of Bill, 63 year old male, GBM, time five)

6.6.2 The strain of the caring role

The level of strain on people as they became carers for their loved varied across participants. Many carers reported difficulties in their new role looking after their loved one,

Cos the the pressure is really enormous, you know, *enormous*. But it's, I've never, I never visualised in my life, having to do anything as difficult as what's happening now you know. (*James, husband of Sarah, 66 year old female, suspected glioma, time one*)

It is stressful there's no argument about it. But at the same time I don't resent it. (*Jim, husband of Mary, 76 year old female, AA3, time two*)

For others, there was not a great deal of change in patients' personality or abilities at this stage and so the pressure to become a carer was not so great. However, in cases where the patient was really quite ill, there were increased pressures on the person closest to them, such as assistance with instrumental activities of daily living, sometimes involving changing gender roles,

It was at least an hour later than I really wanted to depart, when I got finished. Erm, doing household jobs and what have you, you know preparing breakfast and what have you, that's that's alright. [...] Erm, I've no doubt other things that might tire me out and wear me out, like erm, organising the washing, drying of clothes. (*Alistair, wife of Harriet, 64 year old female, GBM, time three*)

Looking after young children also compounded the difficulty of the caring role,

I felt I had to be at the hospital basically from when he woke up til he practically went to sleep at night. Just to make sure he was OK. I found that really stressful because I've got ma own childr, well I've got *our* children, you know, and they were just being left behind. (*Sheila, wife of Andrew, 45 year old male, GBM, time three*)

Acceptance of the caring role combined with renouncing independence also required a process of adjustment. Difficulties that Harry and Ewan had when I first visited them had been ironed out by the time of our final interview,

So psychologically, for me, we've adapted to having [patient] at home. We enjoy having him at home. Er, he's sort of resigned to being at home, certainly for the foreseeable future. And er, has adapted. [...] I think [patient]'s found it a bit difficult but initially, and I did as well I suppose. But gradually we've just developed a good relationship and found our own space.

(Harry, father of Ewan, 21 year old male, GBM, time four)

In other situations, the patient was not prepared to accept they were vulnerable and needed to be looked after, which was distressing for the carer,

That's the bit I found the hardest, because what can you do? You know, you can't do anything. And actually, in a way, he needed me there, he's needed me there all the time, but at the same time, he didn't want me there. He pushed me away.

(Angie, wife of Wilson, 58 year old male, GBM, time four)

In certain circumstances, carers' own health was affected or existing health problems exacerbated as a result of their caring role,

I've got a back problem, I went to the doctor for a yearly visit there just last Thursday. [...] The only answer he's got is an operation. But I told him I says there's no way that I'm going to go through an operation. I go into hospital who's going to look after [name]?

(Jim, husband of Mary, 76 year old female, AA3, time two)

I'm not coping as well as he is obviously. I have been depressed in the past so perhaps that is why I am feeling more depressed than I would like. But it's just, I hadn't really decided what to do, you know, about getting depressants, I don't know.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

6.6.3 Personality and behavioural changes

Dealing with personality and behaviour changes were among the hardest things for carers to deal with,

Horrible. Really. I mean I've, I've known [patient] since I was 15 years old. Erm, and we're 46 now so it's a long time and it's like living with a stranger sometimes. Its really, really difficult to [...] cope wi that part of it you know.

(Sharon, wife of Ian, 46 year old male, GBM, time two)

By the time of our next interview, the pressure of dealing with the changes in her husband meant Sharon is nearly at breaking point,

It's made it sort of, unbearable sometimes. [...] It's hard to imagine being able to live the rest of my life with somebody with that kind of temperament. Because it's affecting my life, it's affecting the children's life for the worse.

(Sharon, wife of Ian, 46 year old male, GBM, time three)

Angie was also dealing with anger and aggression in her husband, which initially she chose not to tell me about. During one of our later interviews, she revealed just how distressing it was,

But he was so, he has been very vitriolic towards me. And that's when I couldn't take it any longer. Which he'd never, you know, I could almost accept it if we had argued during our marriage, but we never did. [...] If [daughter] wasn't living at home, I wouldn't like to say where I would be right now. I'm not proud of it, because you don't walk out on somebody when they are ill. But it's very, it's very hard.

(Angie, wife of Wilson, 58 year old male, GBM, time four)

6.6.4 Respite

Carers tended to focus so much on the patient that they did not attend to their own respite needs, perhaps as a distraction from facing the reality of their situation.

However, over time, some carers recognised their own needs as important,

Friends have lent me films and I've found that really very therapeutic. It's been total distraction for me completely.[...] But erm, I'm watching more than I used to because I'm finding it, erm, a good escape.

(Angie, wife of Wilson, 58 year old male, GBM, time three)

I would like to be able to just go out the house and get into the car and go to the shops and, you know, do some shopping for a couple of hours, like I used to. And just leave the kids with their dad, you know. Erm, but I can't do that.

(Sharon, wife of Ian, 46 year old male, GBM, time three)

Patients were wary of becoming a burden on their loved ones and wanted them to take time for themselves,

But [patient] thinks I need to have some time for myself. He thinks I should go and get a massage and things like that. I will eventually do things like that I think to relax you know.
(Sheila, wife of Andrew, 45 year old male, GBM, time three)

In some cases, as time went on, patients spent time at the hospice day centre,

A: We had a leaflet about [hospice name] Hospice this morning and he is gonnae go to the day hospital. I mean I didn't really, I was not sort of... but when [name] asked you if you wanted to go, you said yes. I said but don't just go because you want me to have a rest.

I: What is your reason for wanting to go to the hospice [to Bill]?

B: Give [Audrey] a break.

(Audrey and Bill, 63 year old male, GBM, time four)

Although carers did recognise their own needs, the patient always came first,

You would go insane if you just stayed in here constantly so kind of, we try to take turns about. But you're always like, oh I need to get back home to make sure everything's alright and that. It's always at the back of your mind.

(Kerry, daughter of Sandy, 47 year old male, GBM, time two)

And I get my day out myself once a month. Well at first I didnae want to go out and leave you but you said I was to go. I always have my phone with me so...I- I phone a couple of times while I am out to make sure he is alright.

(Shauna, wife of William, 64 year old male, GBM, time four)

The demands on the carer, and subsequent need for respite, depended on how ill the patient was and the nature of their needs.

6.7 Summary

As time progressed, participants were better able to reflect on the flattened affect they experienced in the time immediately surrounding diagnosis, highlighting the dynamic

process of adjustment and sequence of emotional reactions captured by the longitudinal method. Experience was also typified as anxious, distressing and worrying as people attempted to make sense of and come to terms with their circumstances – a devastating diagnosis, uncertainty, a complex and difficult illness to live with and a premature end to life. Patients and their relatives employed a range of different coping strategies to help come to terms with their situation including having a positive outlook and fighting spirit; taking it as it comes and living in the moment; distraction; comparison with others; using past experience; and denial and disavowal. In relation to having a positive outlook, hope played a vital role in successful coping. Social and emotional support was also important to both patients and their relatives in most cases, including professional and peer support. Carers had a number of distinctive issues to deal with. Certain aspects of the caring role put an added strain on carers, impacting on their physical health in some cases in addition to the emotional distress. The most difficult issue for carers to deal with was the behavioural change, distinctive to brain tumour patients in comparison with other cancer groups. Carers were unsure about how best to look after their loved one and what to expect from their illness as time progressed. The need for respite was identified to protect carers' own health and well-being.

Chapter Seven: Information and communication

Information available to patients and their carers and the ways in which information was communicated were central to participants' concerns and appeared to relate to coping. The way in which people managed and processed the information they were given was affected by their coping style, with some people actively seeking information and others avoiding it.

7.1 Lack of information

Lack of relevant information was a highly significant issue for patients and their families. People reported feeling like they had no idea what was going on and being left in the dark. Lack of information relates to the feeling of uncertainty, lack of control and the associated distress.

Participants often felt very poorly informed before they had a confirmed diagnosis,

The one thing I will say though is, I didnae think the doctors and that are too forthcoming wi telling you things. Like sometimes you feel like you're dragging teeth to get, to get some kind of information oot of them.[..] I just got a bit of a fright.

(Ian, 46 year old male, GBM, time one)

The distress and uncertainty caused by lack of information was clear,

That was the time when I really thought that was it, I didnae think I was going to get out. You know, cos the guy was, he didnae say too much.

(Andrew, 45 year old male, GBM, time two)

And when you're left to your own devices it's only human nature to come up with the wrong conclusions.

(Jim, husband of Mary, 76 year old female, AA3, time two)

Jim did not feel that they had the opportunity to ask questions and that they were getting mixed messages from the health professionals and no coherent answers.

Another participant described the lack of clarity as she awaited surgery,

They said it would maybe need to be a biopsy but they weren't sure how they were going to do that, so it was a bit sort of [...] it was kind of you know very nice but really I was kind of thinking 'just get to the bloody point' (LAUGHS) 'what's going to happen here'.

(Jenny, 34 year old female, suspected glioma, time one)

During the period before a confirmed diagnosis, the information participants were seeking was largely related to the process of what was going to happen to them. For example, knowing when to expect to hear more information and who will be managing patients' care,

We were told that we would hear [...] within in the next two or three days, you know. Erm, that was Tuesday, we've not heard yet. So it'll either be tomorrow or Monday, Tuesday or summit like that that we'll probably hear. Hopefully, you know as to what's going to happen.

(Sarah, 66 year old female, suspected glioma, time one)

I'm no quite sure who's in charge of me as regards to a senior doctor. I would imagine the surgeon would be out of the picture now. He's already been in and had a shot. So is it the radiotherapy people? Ken, these things are no made very clear. Not that I suppose it matters to them in charge but it matters a wee bit to me.

(Sandy, 47 year old male, GBM, time two)

Certain participants felt that all of the information they were given, including more detailed information about their tumour and prognosis, should have been provided at the earliest opportunity,

I think it was good to get the letters [leaflets] out at the beginning. Everything you can get your hands on if you're keen.

(Bill, 63 year old male, GBM, time three)

I think that I, I think that I should have been told at that stage, more about erm, the nature of the beast, erm, and the seriousness of it. And I still haven't been told anything of that nature by the hospital, I've had to find that out myself on the internet.

(Wilson, 58 year old male, GBM, time two)

However, there was recognition that how they felt at the time could be different. A person's position may change over time and reflecting retrospectively may not give an accurate reflection of how they felt at the time.

Having information reduced anxiety levels and gave respondents a feeling of trust that something could be done to help them,

I like to know, information for me is the best because you cannae be afraid of what you know.

(Sharon, wife of Ian, 46 year old male, GBM, time two)

We had to go back in the next day and we had a bit more detailed information. And from that point of view it was, it wasn't going to be a biopsy, it was going to be a removal. And for some reason [doctor]'s information was an awful lot more positive for us from what we had had the night before. It didn't make it go away [...], but the information I felt was more factual and more specific to me.

(Christine, 37 year old female, AA2, time three)

Having an explanation of what was going on and what was going to happen next was very important to participants and helped them to control their anxiety and build some hope for their future.

Over the course of time, lack of information became less of a generic issue as people were provided with more information about their diagnosis and were able to actively seek additional information. Information needs became more diverse. People began to seek more than procedural information and wanted to know more about what to expect in the future and many asked the question: how long have I got? For a small but significant number of patients, this was a question they felt they would have liked the answer to right away,

They want to know, even at the time, they want to know how long they are going to live and all the rest of it.

(William, 64 year old male, GBM, time three)

There were specific areas, which varied across participants, where people continued to feel that information was lacking. For example, Alistair was ready to hear information about end of life issues but felt this kind of information was not forthcoming. Harry was comforted by resolving unanswered questions about how his son would be cared for at the end of life. David wanted to know what financial assistance was available to him and his sister. For Joan, having information about whom to contact in an emergency would have avoided some distress,

I was thinking, I could have been spared lots of panicking if someone had just handed me a card and said this is what you do in case of an emergency.

(Joan, wife of Malcolm, 41 year old male, GBM, time three)

Alice felt ill prepared for a seizure that occurred and wanted more information on what types of symptoms to expect and how to deal with them,

I would have made it my business to find out how to react, erm, and I would have known that, yes he comes out of it, scary though it is at the time, for the first one. [...] I could have, sort of, erm, got the procedure how to cope with it.

(Alice, wife of Henry, 65 year old male, GBM, time three)

By the time of my final interviews at time four, there were no more direct examples of lack of information although participants continued to encounter problems where information played a key role with examples diffused throughout this thesis.

7.1.1 Information not tailored or specific enough

Some participants felt that although information was being provided to them, it was not sufficiently tailored to their particular diagnosis and treatment needs,

There is just so many different types, that's what I felt, if they could tell us on Wednesday what it is, then you know, you can eliminate a lot of things, you know, and concentrate.

(Julie, wife of Sandy, 47 year old, suspected glioma patient, time one)

I've got pamphlets about tumours and things like that but, there's nothing really in them. It's like generalisations, I think.

(Ian, 46 year old male, GBM, time three)

7.1.2 Dealing with medication

Lack of information on medication from both hospital and primary care - what drugs patients should be taking and correct dosage - was also problematic for participants and posed an ongoing issue,

The only thing was that they had given us a couple of brochures on um brain tumours but they hadn't given us one on the steroids. But then when we saw the nurse after that she gave us one, I think that should have been given to us before.

(Audrey, wife of Bill, 63 year old male, GBM, time three)

Joan described the complexity of Malcolm's medication regime and their perceived lack of information and support in managing it,

Cos it said, what's your medication called? What time of day are you taking it? What's it for? And you can write then, you know, the doctor's name for it, your own name for it. And what's it for. But nobody does that at the [hospital]. And he is taking seizure medication, he is taking steroids, he's taking anti sickness tablets, painkillers and er, something for the stomach cos the steroids can cause ulcers or something. And of course all the vitamins that I am having him take. I felt I said can I get some kind of, you know, guidance.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

Sharon was concerned about the impact of Ian's confusion,

The only one thing I would quibble about a wee bit is erm, when they're, when they're handing out the, the chemotherapy tablets and all the other tablets, I sometimes wonder if they mebbe shouldnae have the person's partner with them at that time. I had to sit doon and read through it and I says well, I think this is what you're supposed to do. 'No, no, they said this'. [...] So he had to phone the hospital back.

(Sharon, wife of Ian, 46 year old male, GBM, time three)

Harry explained how important it was to keep a track of medication, particularly toward the end of life when the range of drugs expanded,

When he was home from the hospice we had a, we made up a big chart of all the times he gets different pills.

(Harry, father of Ewan, bereavement)

7.2 Desire for honest, clear and direct information

Participants conveyed that they did not want information to be withheld, and preferred to be told all the relevant information clearly and directly,

You can't pad it out, you can't cover it up because, it's the bottom line you get. And yes, it's a shock. It absolutely guts you. And but, I mean, well for me, no matter how bad it is I think I'd rather know what it was than have it camouflaged in some way.

(Henry, 65 year old male, GBM, time two)

Sandy did not trust the medical profession as a result of past experience and felt that they were masking something,

They don't give very straight answers. Everything's ifs, buts and maybes.

(Sandy, 47 year old male, GBM, time two)

It was important to many participants to be 'told straight',

The doctor just told us, you know straight out, which ..that's the only way [patient] would huv things. [...] Just as long as we know the full facts and what's gonna happen.

(Julie, wife of Sandy, 47 year old male, suspected glioma, time two)

Although it was very difficult, unpalatable, if you don't know exactly what the situation is, you can't manage it.

(Norman, husband of Winnie, 59 year old female, GBM, bereavement)

However, there were limits to the direct approach,

I appreciate if you are a no nonsense person, but you need to remember this is someone's life you are talking about.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

She managed to erm, assess his character very quickly and I think she just knew she had to sock it to him, you know. Right inbetween the eyes. And it was, it was hard to take.

(Angie, wife of Wilson, 58 year old male, GBM, time four)

Although people wanted honest and straightforward information and communication, they also wanted professionals to acknowledge their distress and be supportive (see section 7.4.2 on communication style).

7.3 Ability to absorb information

The desire for honesty and to be told all the relevant information was complex and intertwined with a protective instinct to avoid any information that was damaging.

When being given the bad news of diagnosis, patients described a shock or 'shut down' where no new information went in after that point,

He was quite OK and he asked questions as though. I kept thinking, how's he managing to take that but it was just I was like, gobsmacked at first.

(Julie, wife of Sandy, 47 year old male, suspected glioma, time one)

You really have to take at least one person. I'm glad my wife comes. I don't take it in, you think you're taking it in but no you're not you know

(Bill, 63 year old male, suspected GBM, time one)

Participants looking back on their experience in the first weeks leading up to diagnosis recognised that they were not able to absorb the information at the time,

Anybody who was talking to me, it was ‘blah, blah, blah’. I wasn’t taking anything in, you know. I was operating on automatic pilot.
(Sharon, wife of Ian, 46 year old male, GBM, time two)

I’m no listening, but I’m hearing it but I dinnae want to take it in. That’s why my husband’s been wi me, listening for me.
(Lois, 50 year old female, GBM, time three)

For some patients, potential cognitive effects of their tumour or medication made it hard to retain information,

Oh I cannae remember speaking to him. That’s the funny thing, I mean, there’s days for me that just dinnae exist really. I cannae remember them. They’re just a blur because of what was going on.
(Barbara, 45 year old female, oligodendroglioma, time two)

7.3.1 Readiness for information

Participants were also aware that they may not be ready to hear particular types of information at certain times in their illness trajectory,

Part of you’s frightened to ask too much cos you don’t really want to know.
(Ann, 66 year old female, suspected glioma, time one)

Do people recover, you know, when it affects that part of the brain, do they get those functions back? Or is that them lost forever? Maybe I’m not doing it because I’m scared to ask, scared what the answer’s going to be, you know.
(Sharon, wife of Ian, 46 year old male, GBM, time two)

In some cases, keeping knowledge at bay and putting thoughts of what was happening out of their minds helped people to deal with things,

I didn't want too much information to come that many weeks before the operation. Maybe the week or a few days before the operation, I was ready to hear it all really. [...] I just wanted to spend the time thinking about something else, thinking about my every day things really.
(*Malcolm, 43 year old male, suspected glioma, time one*)

There was a feeling among participants that too much information could be harmful to them and their ability to cope,

Sometimes too much information can be quite harmful too.
(*Sandra, 46 year old female, suspected glioma, time one*)

I want him to get the information he wants. But not, more information than he wants. [...] I knew it was good news I'd want more information, you knew it's bad news you do not want the information. So what do you do?
(*Harry, father of Ewan, 21 year old male, GBM, time three*)

It is possible that people needed time to come to terms and digest each piece of information one at a time and to have emotionally processed the meaning behind the diagnosis before they were receptive to hearing new information.

7.3.2 Reading between the lines

There were certain questions that some participants were afraid to ask and so they made inferences about the issues they were most scared of knowing the answers to; essentially related to the questions: 'am I going to die?' and 'how long have I got?' Participants appeared to 'read between the lines' of what health professionals said to them in order to indirectly access the painful truth of prognosis that was too frightening to face outright and likewise to look for signs of hope,

It was only when the nurse phoned on Friday and said we had a holiday planned for September would it be alright to fly. And she said 'oh yes that would be fine' she says you know. And so then we thought, well does that mean we've got until September?

(Audrey, wife of Bill, 63 year old male, suspected glioma, time one)

It's things like that, little phrases, you have to hang onto.
(Angie, wife of Wilson, 58 year old male, GBM, time two)

I mean nobody has said to me, you are going to die. But as I say that is my analysis reading between the lines of these books.
(David, 48 year old male, brain stem glioma, time two)

You know, it's silly things that make you think well that's good. Do you know what I mean? That your next appointment's for February. Cos then he said to me, which he has never said before, he goes, I didn't think I was going to be here for Christmas.
(Sheila, wife of Andrew, 45 year old male, GBM, time three)

7.4 Importance of reassurance and positive information

Reassurance and positivity reflected in the information given and in the style in which it was communicated were significantly valued by participants and gave them a feeling of recognition and involvement. Managing information in this way appeared to be linked to an overwhelming desire to be told everything was going to be okay, possibly connected to hope and disavowal. Participants were very reassured and found it easier to cope when the health professionals they interacted with were positive and encouraging,

P: The surgeon was very up and very positive
C: So I think the th-the thing there as well you know, it could have felt a lot harder. It hasn't. And a lot of that has been through positive approach by the team and Ward [number] and Ward [number] and positive approach by [patient] and the rest of the guys round about.
(Sandra and Stuart, 46 year old female, suspected glioma, time one)

She says 'I'm doing this on a regular basis and er, it goes smoothly. And I've no reason to believe it won't go smoothly with you'. So then the positive side came out and that made all the difference, you see.
(Ann, 66 year old female, suspected glioma, time one)

Reassurance from others was central to helping people feel supported and more able to deal with the seriousness of their situation. People sought reassuring information and avoided anything that could 'bring them down',

Because I've got er, a lot of family involved in stuff, people will phone you and talk about where are you're having it done and stuff like that. And then they know somebody who had something like this done and they know someone who's particularly good somewhere else. And I found, you know, they were trying be helpful but it's not. When they tell me there's someone else that could do it, that's not an option for me. The most comforting er, things were when people were saying er, '[hospital] is really good'. And 'I know somebody who's been through [hospital] and it's been (good)'.

(Henry, 65 year old male, suspected glioma, time one)

The reassurance sought at this stage was all relevant to the process of surgery, treatment and diagnosis and therefore suggests that timing and relevance of reassuring information was crucial.

Another carer described how reading positive and uplifting stories helped boost morale as well as educate and empower her by giving an insight into what to expect,

But er, well I think I gained from it you know, a little bit of how things might be after the surgery. And, and you know, the emotional part of it for the person going through. Cos that's something I really want to understand so I can help as much as possible. [...] I developed a shield or something. Cos I just see what I find useful and I don't look at the rest.

(Joan, wife of Malcolm, 41 year old male, AA3, time two)

Later interviews revealed continued benefit from reassuring talk from health professionals,

I think what helped also because all the staff there said how well you had coped with it.

(Alice, wife of Henry, 65 year old male, GBM, time three)

But then I don't think you'd want it to be too doom and gloom in case it frightened you too much. I think they need to give you something positive to hold on to something that's going to lift your spirits a wee bit.

(Audrey, wife of Bill, 63 year old male, GBM, time three)

7.4.1 Lack of reassurance

Lack of reassurance, on the other hand, was very distressing for some patients, perhaps taking away their ability to hope,

Um you know we've found a tumour and my mum said well is it is it benign, and he said well no brain tumour is benign. And I kind of, I kind of understand what he means by that. But I was kind of left feeling totally dismayed.

(Jenny, 34 year old female, suspected glioma, time one)

Sheila felt angry and very distressed that the hospital weren't doing enough for them when perhaps the reality was they were telling her something that she did not want to hear,

The doctor there had said you know, we are no doin' any more treatment and stuff like that. I wasnae havin' any o' it. I said I am no ready to give up, she was 'No, no, no, things can change' and whatever. But 'Y'know where we are at the moment, y'know, we can't do anything'. She was basically closing the door there to begin with. I just lost trust. I wanted them to be more positive for us.

(Sheila, wife of Andrew, 45 year old male, GBM, time three)

Will I be here this time next year? And the answer was you have got a 10% chance. Erm, and I don't think that that is what someone who's just come out of treatment wants to hear. Erm, or should hear.

(Wilson, 58 year old male, GBM, time four)

7.4.2 Communication style

Much of reassurance came from good communication style. Kindness in the manner of health professionals went a long way to making people feel reassured,

It does help a lot, you know, it helps to make the patient feel better as well actually. You know and they can sort of communicate with somebody and have a smile.

(James, husband of Sarah, 66 year old female, suspected glioma, time one)

Reassurance helped people digest the unpalatable news of diagnosis,

He is such a warm person. And makes you somehow just, you can trust him. You know that you are in very good hands and he kind of radiates that presence. So I think that affects how, when we were talking about this. I must admit, made it much easier to, to listen to this news.

(Joan, wife of Malcolm, 41 year old male, AA3, time two)

The ability to communicate bad news in a positive light changed their interpretation of what they were being told and allowed them to maintain some hope. This contrasted with negative experiences,

I felt, you know, like I was being patronised really.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

Yes, I mean, basically I just, well, [doctor] didn't have any sort of bedside manner. Erm, it was terrible.

(Wilson, 58 year old male, GBM, time four)

7.5 Becoming experts

As time progressed, information was more freely available to the majority of participants as they adjusted to their illness and learned more about how the system worked. People were therefore more confident about asking questions and accessing and controlling the information available to them. More questions were raised, particularly by carers, as people learned more and were more actively involved,

I came with, on the last one, with my list of questions. [...]I asked, I wanted a bit of clarification about why they are not recommending chemotherapy at all, at this stage.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

As time passed, participants reported gaining information from health professionals involved in their care, newspapers, books, the internet and friends and family members with expert knowledge,

A: At first I knew nothing about it but, that is one thing over the months you do yes.

I: You learn quite quickly.

A: You just have to.

(Audrey, wife of Bill, 63 year old male, GBM, time four)

Participants such as Audrey became more critical in later interviews as they were more confident about what should be happening and perhaps more open in interviews.

As people became more expert, information needs changed accordingly and they became ready for more detailed information,

It would have been useful, I felt, to have been able to compare the two and to have had some explanation as to, erm, why they were the same, why they were different, whatever. Erm, just to have sat down and said, right, you know, with pictures as well, this is what, where it is, what it was, it's in your temporal lobe. More about what was done to get it out or to erm, I mean they've sort of scratched around the surface of that.

(Wilson, 59 year old male, GBM, time four)

So just really, you've been looking to see, educate yourself more I guess, about the whole area.

(Alice, wife of Henry, 65 year old male, GBM, time four)

On occasion, some participants still felt isolated and unable to access information about what to expect,

I must have admit, that's my one bug bear about the whole thing, the lack of information. I mean, fair enough I've got pamphlets about tumours and things like that but, there's nothing really in them. It's like generalisations, I think, it lets you know what this tumour is.

(Sharon, wife of Ian, 46 year old male, GBM, time three)

In this particular case, the couple had three young children and lived a distance away from the hospital, thus Sharon had not been able to attend with her husband and became isolated from the provision of information and support.

7.5.1 The internet as a source of information

Part of the process of becoming more expert in glioma was to consult the internet in order to gain information,

To be honest, you can get all that on the internet now, all this information. Everything is on it so there is no hiding place for that y'know.

(Andrew, 45 year old male, GBM, time two)

I have ordered some supplements from the internet that have been shown to have good results and help a lot with immune system and that. And also working good for glioma.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

There was a definite awareness among participants that internet information was to be treated with caution and it was possible to come across harmful and unhelpful information,

I've looked at my symptoms on the internet before. And sometimes I don't think it's such a great idea.

(Jenny, 34 year old female, suspected glioma, time one)

It really should be funneled through one person who is capable of discarding, I suppose, stuff that's not gonna be helpful.

(Henry, 65 year old male, GBM, time two)

7.6 Differences in approach to information

In some cases, participants had different approaches to coping, particularly in relation to how much information they wanted to know and or actively sought. Moreover, people recognised that while they stated a particular preference, not everyone in their position would feel the same. Pro-active information seeking appeared to be linked to coping and the need to re-gain control whereas others avoided information and were not prepared to process the painful reality of what was happening.

Participants' over all approach to information-seeking appeared to be relatively stable over time. There was a notable gender difference in approach to gaining information with males seeming more likely to seek information. Moreover, patients and carers of a younger generation (under 60) appeared to be more pro-active in their information seeking. Additionally, patients who were more ill were more likely to have a carer acting on their behalf to gain information and manage their illness.

In some cases, patients sought information about what to expect while their relative avoided distressing information,

If she tells me that's fine, it doesnae really worry me because y'know, you want to find out anyway. But I think [wife] she's the other way. She would rather we just keep it going y'know.
(Andrew, 45 year old male, GBM, time two)

R: Er, what I'm gonna ask, I have asked the doctor what happens when-
B: Well, I'll be leaving the room. I just feel people shouldnae say stuff like that.
(Ron and Betty, 64 year old male, GBM, time two)

Some carers were protective of patients and shielded them from information they may not wish to hear,

Is she gonna be here in 3 years time? Is she gonna be here in 5 years time? She's only 50, there's a lot of years in her yet. [...] But wi that, what am I looking at? But every time I've been with [patient], you're no wanting to ask any questions in front of her.
(Steven, husband of Lois, 50 year old female, GBM, time three)

I mean, that's what's breaking my heart the most is, what are his chances? Certainly the leaflets I saw were pretty horrifying. I'm sure [patient] is aware, but I don't know if he's blocking it out or not, how serious and how short the life maybe.
(Harry, father of Ewan, 21 year old male, GBM, time three)

Alice was unhappy about the reading that her husband had been doing to find out more about glioma and what to expect, something she would rather not know,

Well he does it when I am in bed. I don't know the total extent of it all, but I just see the odd piles of papers that don't move. So he is not actually working with them all the time. I think, well that's not good.

(Alice, wife of Henry, 65 year old male, GBM, time four)

However, there were cases where female carers and patients also sought detailed information,

It's just different ways of handling things. [...] Because he, you know really just said, I don't want to think too much about it.[] He didn't really want to discuss it. And I didn't really want to discuss it with him because you know, because I feel, at least that's how he wants things. I fully understand that.

(Joan, wife of Malcolm, 41 year old male, suspected glioma, time one)

And, reading, I feel that it's not working well on me. It starts making me anxious and so on so. So I decided to just stay, and she helps to, she likes it you know, she feels better doing it but it er, it works the opposite way on me. I don't want to.

(Malcolm, 41 year old male, AA3, time two)

Variance in approach to coping and individual differences across people in general were also recognised,

I like having people around and I like having people that'll phone and say are you alright. But not everybody is the same as me, you know, because some people would rather keep it to themselves and not do very much else with it.

(Christine, 37 year old female, AA2, time three)

7.7 Summary

Patients and relatives felt under-informed at all stages of the illness journey, particularly in the period leading up to a diagnosis. Participants reported that

information provided was too general and not tailored to their specific needs. People also required more information on specific issues such as use of steroids and other medication. The majority of participants expressed a desire for honest, clear and direct information. However, this was qualified with a concern that the information could be damaging or not what they want to hear; resulting in a tension between wanting and not wanting to know. People latterly reported that they may not have been ready to hear and absorb particular information due to immense shock and distress. Patients and relatives wished for positive information that was communicated in a reassuring and sensitive way. Procedural information about what was going to happen in the course of their investigation and treatment was also requested. There was a more mixed feeling about detailed information about the disease itself and what to expect upon its progression. On the whole, participants did not want information to be withheld from them but were more reticent about receiving these kinds of details. Information needs differed across individuals such as differences between patients and carers, with carers sometimes seeking more detailed information. Over time, many participants had built up a framework of understanding and gained confidence and expertise in their knowledge through more proactive participation in consultations.

Chapter Eight: Managing and controlling illness

This chapter covers more practical impact on life as patients and carers adjusted to glioma, presenting findings mainly from the interviews after a diagnosis was confirmed. Many participants attempted to adapt and return to some semblance of life as it was before illness. Ability to return to normal varied depending on the extent of patients' physical and cognitive symptoms and perceived ability to accommodate their illness.

8.1 'Biographical disruption'

This section outlines the disruption encountered by patients and carers, preventing them from performing their usual social and work activities,

Because that's one of the hardest things to deal with, is to let go of how ordered your life was before and you know, you knew what you were doing from one week to the next. And you paid your bills every month. All that's gonna change and it's, it's adjusting to that that's the hardest thing.

(Sharon, wife of Ian, 46 year old male, GBM, time two)

The extent of this impact varied from person to person and over time: patients had the initial recovery from surgery; the after effects of treatment; and the gradual decline in cases where the tumour recurred.

8.1.1 Work life disruption

For most patients of working age, their illness meant a very sudden change to their working lives, which was difficult for many to come to terms with,

I'm not working and that's what gets me really down.

(Ian, 46 year old male, GBM, time two)

So it was a real culture shock y'know. Em...and as I say, all of a sudden nothing. That was a real strange one.

(Andrew, 45 year old male, GBM, time two)

However, for Andrew and others, work became a lesser priority; suggesting a shift in priorities brought into focus by their devastating diagnosis,

I mean people always go on about you are nothing if you haven't got your health. [...] To be honest it's funny because normally you know, being a workaholic, you tend to think a lot about work. Now, it's been kind of strange, the period being off. I really don't think about work at all.

(David, 48 year old male, brain stem glioma, time three)

The cancer hanging over him all the time must be very difficult. [...] So you know, difficult to work up enthusiasm to you know, get a career or something like that. So that whole area is a bit unknown, really, I'm a bit uneasy about it.

(Harry, father of Ewan, 21 year old male, GBM, time four)

However, some considered a return to work as their condition improved,

Well you have started to do a bit [of work]. And I think that is something you build up. But you can't do everything. [...] Your priorities kind of change.

(Alice, wife of Henry, 65 year old male, GBM, time three)

For others this was not an option,

I've not started work yet, I don't think I'm ready for that. If I've not to lift a Hoover in here, or climb, then there's no way I'm ready for [work]. No way.

(Deirdre, 56 year old female, GBM, time three)

8.1.2 Personal and social life disruption

In addition to working lives, people's personal and social lives were also affected.

Participants became socially isolated as they were prevented from going out and engaging in activities they previously took for granted,

We havenae got any social life because we're no really, I'm not fit to do a lot of things.
(*Deirdre, 56 year old female, GBM, time three*)

We stopped doing that because it's ...erm, likes the pubs and all that sort of stuff, just gave up that because you cannae really get into that at all.
(*Andrew, 45 year old male, GBM, time three*)

Participants valued occasions when they did go out and socialise and were bored by being idle.

Some participants made changes to major life events,

Yeah our daughter's brought forward her wedding to October just because when we asked them they did say well if you're feeling better now it's maybe better to have it now um rather than leave it and then maybe you wouldn't be feeling so well.
(*Audrey, wife of Bill, 63 year old male, GBM, time three*)

As time moves on, some participants became increasingly socially isolated due to deteriorating mobility,

I'm seeing people in a different context, but they are kind of one-off things as opposed to like a normal social life. [...] Cos, I mean, I, the types of stuff I was doing that I mentioned earlier, the exhibitions, you know, book shops and things, I'm just not able to do any more. So, er, you know, gradually I suppose, I've been cut off from society that way.
(*David, 48 year old male, brain stem glioma, time four*)

8.1.3 Not being able to drive

The impact of not being able to drive was not to be underestimated. It took away independence, normality and control as well as impacting on ability to work for some participants, with practical and financial implications,

The only trouble is that you can't drive eh, this is the only thing. Which is a bit of a pain. It's a..a b-bit annoying because ...ma-my son was working with me and he can't drive as well so it is a bit of a mix up y'know. But unfortunately that's the way it is.

(Andrew, 45 year old male, GBM, time two)

It's just frustration at not being able, not being *allowed* to drive. Erm, because that means I can't get myself into work, I can't go and do things that I want to do. I am reliant on other people and public transport all the time. So that's very frustrating when I feel perfectly capable of doing it. [...] That is the most annoying feature of this.

(Wilson, 58 year old male, GBM, time three)

8.1.4 Loss of independence or dignity

Becoming more vulnerable and having impaired abilities was difficult for patients to deal with, particularly when it came to self care and, in the following examples, loss of mobility,

I feel embarrassed at times. Yeah, you know in a wheelchair. I've seen people in a wheelchair but when it's yourself you feel different.

(Mary, 76 year old female, AA3, time two)

She said no to nearly everything (the Occupational Therapist offered) because she said I want the challenge of trying to do these things. I don't want to give in.

(Alistair, husband of Harriet, 64 year old female, GBM, time three)

Maintaining independence over time was very important to patients,

Obviously I want to remain independent. Erm and that, I mean, I couldn't rely on my sister to be here everyday or whatever. [...] So I mean there are things that I notice for instance, getting dressed and that sort of stuff is not getting easier. I do obviously want to remain that I can do it myself as long as possible. When I say as long as possible, I really mean like forever. I mean, er, the prospect of not being able to do something as simple as that I would find really terrifying.

(David, 48 year old male, brain stem glioma, time three)

Lack of control was a source of frustration, distress and indignity,

I'm finding it difficult to live in this kind of state. Erm, I hate being like this [...] No being in control of myself.

(Sandy, 47 year old male, GBM, time two)

I: What would you say has been the most difficult thing throughout your illness to deal with?

(Long pause, visibly distressed)

B: Phew, not being in control, y'know.

(Bill, 63 year old male, GBM, time four)

Others (often those with good function) were often more accepting of help,

No. You just get on with it. She's been really good, but that's amazing really. Er, I'm quite into this breakfast in bed (laughs).

(Henry, 65 year old male, GBM, time two)

When patients required help with core activities of daily living, distress was more pronounced.

8.1.5 Disruption to carers' lives

The practical impact on relatives' lives was also apparent. For example, there was an imbalance in domestic roles,

We always did everything between us, you know. The cooking, the washing. So, you know, he would, at the weekend, take one of the kids and away and do the shopping, you know. Erm, I have to do all that now.

(Sharon, wife of Ian, 46 year old male, GBM, time two)

It is just, it is horrendously busy, you know, obviously because you forget that you share things so much.

(Audrey, wife of Bill, 63 year old male, GBM, time four)

Carers often had to adjust their working hours or give up their own jobs entirely to look after their loved one at home,

I'm just going to suspend it (university) for this year cos it was my honours, you know, it's just so much work and I was like, there's no way I could concentrate. I just missed so much from the start [...] There was just people coming in and out constantly and then running back and forward to hospital. And it's just too much so it just seems so irrelevant just now anyhow.

(Kerry, daughter of Sandy, 47 year old male, GBM, time two)

I'm still working erm, and the nature of my work, I can bring, I can do a lot of it here. But there's a lot of it I can't do here.

(Alistair, husband of Harriet, 64 year old female, GBM, time three)

In cases where the patient's illness was stable and not causing them difficulties, the lives of those around them were not affected to the same extent,

It's not affected me really at all, because he's so, become, because we've got our own space and he does his own thing, I do my own thing, it's not affected me adversely, my social life.

(Harry, father of Ewan, 21 year old male, GBM, time four)

8.2 Uncertainty about the future

Uncertainty was enduring for people throughout their illness. While participants in the earlier phase of their illness were unsure about their diagnosis and the process of what was going to happen to them as well as fears of the future and dying, uncertainty in later interviews was overwhelmingly dominated by fears about the future including recurrence, deterioration and dying,

So there are no numbers, there are no years, it is just the uncertainty.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

You know, you just don't know how the, what the outcome of this will be. Because I mean, as I say, my mobility is getting worse but that does not mean it is not going to get better.

(David, 48 year old male, brain stem glioma, time three)

For others, there was a latent anxiety surrounding what might happen to them in the future. Wilson adopts a 'wait and see' policy that was perhaps masking an underlying fear,

I don't know. Erm, .. I'll have to see. Erm, that's what I said earlier, you know, when the pain starts, what do they do? Erm, .. when I start losing my facilities, what do I do? I don't know. Erm, wait and see.

(Wilson, 58 year old male, GBM, time two)

A small number of patients voiced concerns about what might happen to them at the end of life,

Well I want to know what's going to happen at the end how painful its will be that's what's worrying me. What's the progression? What happens, you know.

(Bill, 63 year old male, GBM, time three)

What are the things that could happen? I mean, what, is it going to be a stroke or is it going what? It might be a bit morbid to start thinking what will it be?

(Henry, 65 year old male, GBM, time three)

When following up participants at time four, there was less talk of uncertainty. This was perhaps not because the unknowns had become less, but because participants accepted that this part of their life would always be there. Uncertainty continued to be expressed in terms of the resulting distress and existential pain that people were feeling.

8.2.1 Fear of recurrence

Another focus of uncertainty was a latent fear of recurrence, which again became more prominent in later interviews,

That's (recurrence) my big fear

(Bill, 63 year old male, GBM, time three)

Wilson was candid about his fears,

I think probably, that it's just normal and I am fine. But at the back of my mind, always the thought, now is this the cycle starting again.

(Wilson, 58 year old male, GBM, time four)

Participants worked hard to put it out of their minds,

Of course, you know, every now and then you have your doubts and your niggles, but then you have to slap yourself and say, stop it.

(Angie, wife of Wilson, 58 year old male, GBM, time three)

Well sometimes it creeps in and it creeps out again and well, you think about it fleetingly and you think, that's a long way away. And I am just dealing, [...] I know being ready for something is useful and helpful but, erm, there is no point in worrying about it.

(Alice, wife of Henry, 65 year old male, GBM, time three)

Interestingly, when recurrence did happen, participants did not describe to me a defining moment with the same acute distress as experienced when they were first diagnosed, perhaps because the expectation was already there, unlike many other cancers. The news that the tumour had progressed came more as an afterthought as the patient's deterioration was obvious before that point.

8.3 Physical and cognitive symptoms

A large proportion of patients' distress and struggle with dignity and independence was related to dealing with physical and cognitive symptoms. Patients and their

relatives reported a range of symptoms and side effects²¹. There appeared to be a wide variation in quality of life experienced as a result of presence or lack of debilitating symptoms that endured over time. Those participants with fewer symptoms appeared to cope better and have less anxiety as well as an ability to return more closely to life as it was before diagnosis compared with people with more profound deficits.

8.3.1 Nausea and pain

He started radiation treatment, [...] and on Saturday he was sick, really bad headache and he was throwing up as well. And I knew that was a bad time because it can be very dangerous if you have a brain oedema.

(Joan, wife of Malcolm, 41 year old male, AA3, time three)

Just looking for it [increased headaches] perhaps is the, I don't know how real they are. Over the course of the year I have been looking for it. But I don't know what I am looking for really.

(Henry, 65 year old male, GBM, time four)

8.3.2 Seizures and black outs

And then eventually all the seizures started coming back again. And they were just like happening all the time. It was like day and night, I mean, God, a whole weekend. There was one weekend, he had 26, it was just like unbelievable.

(Sheila, wife of Andrew, bereavement)

David and others were very unsettled by a black out episode which shook his confidence and made him very anxious about it happening again,

I was really quite terrified in a sense that, I've seen this coming in, as I say, from the side, totally unpredictable. I mean, that really was dominating my thoughts, you know. Every time you go

²¹ Problems with personality and behaviour change have been reported in chapter six, and were usually voiced as more distressing for the relative than the patient.

to the toilet, I think, you think er, suddenly gonna black out. Now I've actually managed to put that to the back of my head. Erm, but I mean, it's still obviously there.

(David, 48 year old male, brain stem glioma, time four)

8.3.3 Hair loss

Hair loss as a result of surgery and radiotherapy was also a source of distress for a small number of participants,

Mebbe other people think, well it's no that bad. And neither it is, I'm not ashamed, er, I can sit quite comfortably in the house and answer the door. But I would nae go out like this.

(Deirdre, 56 year old female, GBM, time three)

Deirdre was impressed by the wig service offered to people suffering hair loss and she did use her wig for trips out of the house.

8.3.4 Fatigue and sleep disturbance

Fatigue was also debilitating for patients,

Sometimes you have days where you are really tired and other days you are fine. You know, you just cannae explain it.

(Andrew, 45 year old male, GBM, time three)

Sometimes I get a bit tired. [...] I think, the first few (treatments) I didn't really feel it. But the last couple I've felt a bit tired.

(Ewan, 21 year old male, GBM, time four)

Sleep disturbance was also problematic,

When I go to my bed it's like, I lie back and my eyes just ping open. [...] It's like my mind wants to get up in the morning but my body's just not able to dae it.

(Adam, 28 year old male, AA2, time four)

8.3.5 Memory and cognitive deficit

My memory is no the same, no the same as what it used to be like. Like, as I say, the stamina memory ken, trying to read things, you just, you read a wee bit and then you get fed up with it. Concentration is no there either.

(Robert, 36 year old male with a GBM, time two)

Sometimes there's a change in my concentration. I used to love doing Sudokus. I've since done them but my concentration does nae seem to be there. [...] It's just a minor thing. It's not something that would affect your life.

(Deirdre, 56 year old female, GBM, time three)

8.3.6 Mobility

Maybe at the start it was a bit hard cos like eating your dinner with the opposite hand. That's still a bit of a problem, I'm getting there with that. Brushing your teeth, silly wee things like that ken? You know, well brushing my hair, I just cannae. Like washing and showering, I mean, from the start I would really say, I got stuck into that myself. I wouldnae take, no I wouldnae take any help.

(Robert, 36 year old male, GBM, time two)

Being confined to a wheelchair was very difficult for Bill²²,

I: How has it been coming to terms with the loss of mobility for you?

B: Quite difficult, mmhmm.

I: Could you say anymore about that?

B: (Laughs)

A: Quite depressing at times eh?

B: Mmmhmm.

(Bill and Audrey, 63 year old male, GBM, time four)

8.3.7 Speech and language problems

Expressive dysphasia was a source of distress for patients and carers,

²² Whether Bill's lack of communication was down to organic disease or an emotional response is unclear.

I think it is very difficult because <patient> is a great communicator and um very lively vivacious person with a lot of personality. And um also very clever with words, very clever... could use words to great effect...

(Norman, husband of Winnie, 59 year old female, GBM, time two)

I find it hard, you know. And you know and I already know the answers.

(Winnie, 59 year old female, GBM, time two)

When you are starting a sentence, er, and you can't think of the right word and you come out with some, you tried desperately. You know and I can see you being annoyed with the situation intensely because you can't think of the right word.

(Alistair, husband of Harriet, 64 year old female, GBM, time three)

8.4 Aspiring to 'normality'

Although the theme of normality dominated in interviews after treatment, there was strong desire to get better in the earlier interviews,

I just want to get better noo. I feel I'm on this road and I just want to keep going.

(Ian, 46 year old male, GBM, time two)

Getting back to work was seen as a benchmark for normal life,

Just now, and just looking forward to getting it all started and just getting it all finished and getting him all well again. Just be great to get him back to his work that would be brilliant.

(Sheila, wife of Andrew, 45 year old male with a GBM, time two)

It was important to participants to try to restore normal life after treatment, but this was dependent to an extent on how well people were,

But we also were determined to keep life going and as normal as possible. And particularly again, once she'd got through the radiotherapy. Erm, so she went to a concert. Erm, but she, we went to, well, when the [art gallery] reopened, we went there. And erm, we went to a number of things like that, erm, to keep going.

(Norman, wife of Winnie, bereavement)

But it's now over a month since it stopped and he's just going from strength to strength and it's wonderful. This is like a sort of honeymoon period, if you like, you know, until they take the scan again.

(Angie, wife of Wilson, 58 year old male, GBM, time three)

Talk turned away from the illness itself as people were able to make some plans again for the future,

I do want a bigger house and that eh. I don't know whether if he gets a job up here and we manage to dae it that way. Like buy this house and then like, once we've got some of the mortgage paid on this, upgrade. We're definitely looking towards something like that.

(Cindy, wife of Adam, 28 year old male, AA2, time four)

However, this was a case of a person with a low-grade tumour. People in this position would be more likely to have a longer period of stability and be able to plan ahead although awareness of prognosis could also be related.

8.4.1 Struggling to achieve normality

For those with more debilitating symptoms, getting back to normal was more of struggle and required small steps to do tasks previously taken for granted,

I think there's things like er if I'm making a meal now if there's things you can do with one hand then <patient> will do those. And that's the sort of split we have. Actually I buttered your bagel today but normally you've started doing that.

(Norman, husband of Winnie, 59 year old female, GBM, time two)

This struggle was frustrating, particularly in cases of younger patients where deteriorating health went against all expectations,

Just been trying to get my fitness levels back up really, but it's no happening. Erm, I mean I'm even trying to, when I'm in the house, I've even try to keep walking them but I keep getting pains in front of my legs. It's quite irritating cos it means I dinnae walk for long eh.

(Adam, 28 year old male, A2, time four)

For certain patients with considerable physical or cognitive disability, there was often no talk of getting back to normal. Instead they were consumed with planning aids and coordinating care. For Jim and Mary, who were an active elderly couple, life changed immeasurably and Jim felt the pressure as a carer,

It's got to the extent I'm just scared of goin' an leaving her. And when I say leaving her, even going, you know, in a different room.

(Jim, husband of Mary, 76 year old female, AA3, time two)

Another participant reported in earlier interviews how surprised she was at her husband's ability to get out and about and have a reasonable quality of life but when she reflected back on their experience after her husband had died, she felt differently,

It wasn't really a lot of quality time, you know. Some people get a wee bit respite in different things and they can do things, even have a wee holiday. But there was nothing.

(Audrey, wife of Bill, bereavement)

However, even for those with more debilitating symptoms, getting back to normal was still an aim,

And just a case of just, well I think what we're trying to do, is try and get back to a normal life as soon as possible. We know it will take a while like, but just keep going.

(Robert, 36 year old male with a GBM, time two)

8.4.2 'New normal'

People were willing to adjust their expectations and settle for 'almost normal' or a 'new normal' in terms of getting back to how things were before,

He's resumed it slowly back. I think, yeah, but now he's back to, not to all, not to everything, but most of it. He's taken over the washing again, he's doing vacuum cleaning on Saturdays. Yeah and cooking 3 times a week and so on. So he's almost back to normal in that.

(Joan, wife of Malcolm, 41 year old male, AA3, time two)

A: It's fair enough you're more tired but it's not desperate, you're able to do quite a lot.

B: I'm still playing a bit of golf and cutting grass and things.

[..]

A: He's got back to a wee bit of normality now.

(Audrey and Bill, 63 year old male, GBM, time three)

Ron had a determination shared among others to make the most of his new level of ability,

Well, it's a challenge I suppose eh, trying to get back to, which I don't think I ever will. [...] It's like er, Bonny Steele said, I'll never ever be the man I was again, ken. And just, what do you cry it? Be the man you are now.

(Ron, 64 year old male with a GBM, time four)

8.4.3 Adaptation to new abilities

Part of the process of getting back to a 'new normal' appeared to be about accommodating symptoms and adapting to one's new abilities. Patients reasoned that life must allow for disability, for example, not being able to do their old job,

I'm not saying I'll no work again. I might just have to look for something else.

(Robert, 36 year old male, GBM, time two)

William was still able to make trips into town as he did before, but with the aid of a walking stick,

I use a walking stick. [...] And it's handy just for the balance side of it. [...] When you do these kind of things, you've got to be sensible about it. You've got to take the precautions before, there're things you just can't do that you've got to work round. [...] You have to change some things in your life.

(William, 64 year old male, GBM, time three)

Others commonly made sure that they had someone with them,

Erm, I've not to go to the shops on my own, which is, which is OK. I suppose if you did have a wee turn you'd be saying oh dear God. But it's handy to know there's somebody there. Even, even if they're waiting outside a shop, it's handy to know.

(Deirdre, 56 year old female, GBM, time three)

8.4.4 Environmental adaptations

In addition to physical and psychological adaptation to their illness, participants had organised, either independently or in conjunction with occupational health and social services, to have some adaptations to their houses. There were very few problems reported in relation to sourcing aids and on the whole participants were satisfied,

My son in law, well <patient>'s son in law really has been, he's a plumber and he's a great guy, so he's put a step in the shower he's taken off the side of the shower. Um we've done a lot that's made life easier.

(Norman, husband of Winnie, 59 year old female, GBM, time two)

Since you were here last time, we've had actually two new bars added to the door, right door and front door. And today actually just half an 'oor before you arrived they were putting in an extra banister rail.

(Jim, husband of Mary, 76 year old female, AA3, time two)

Although Bill and Audrey had problems accessing equipment within an appropriate time frame in the earlier part of Bill's illness, Audrey described how they were provided with all of the equipment they needed to be able to care for Bill at home to allow him to die at home,

He wasn't swallowing his pills terribly well, they've put some of the medication in a syringe driver, that's that little bag. I mean, we've always got the best of equipment because we didn't have such a good bed before. But they got us the best bed, this is electric now. The other one you had to pump with your foot, this is an electric hoist, which, again, we had a hand one.

(Audrey, wife of Bill, 63 year old male, GBM, time five)

8.5 Finances and social circumstances

On the whole, financial concerns were not a high priority for participants compared with emotional concerns. However, some families did have financial issues, particularly those who were self-employed, had limited sick pay and had young families. In terms of financial support available, there were mixed experiences. For the most part, people felt adequately informed and able to access what was available to them,

But is it [nurse], she's helped us out with forms and everything to fill in. For benefits and that.
(Ian, 46 year old male, GBM, time two)

I got an extra benefit, it does help, it makes a difference. [...] They are all there to help if you read the notices and that. It does make life more liveable.
(William, 64 year old male, GBM, time three)

This information came from a variety of sources including the specialist nurse, GP, community palliative care nurses, Maggie's centre, citizen's advice, support agencies directly or advice from friends and family.

However, Andrew and others did not feel that the financial help available was sufficient,

I: So do you feel that you are getting the benefits that you are entitled to?

P: No, no really, no. [...] I think, I think if you have worked all your days and all of a sudden you have got to stop for whatever period of time, I think you should get all the help you need.[...]
It just doesn't make sense.

(Andrew, 45 year old male, GBM, time three)

The practicalities of filling out forms was also problematic,

It's just actually getting your head round it all and then making the phone calls and finding out. I had to get all these forms filled in which was like, oh my goodness, it was like bamboozling for [patient] straightaway, just to look at it, he was angry.

(Sheila, wife of Andrew, 45 year old male, GBM, time two)

Dealing with finances was also difficult, particularly for younger patients not working with a family to support,

But with this disability to be truthful, it kind of, seems to help a wee bit doesn't it? Disability money. Like we've got a mortgage just the same as anybody, ken like. [...] Er, so no, financial wise, it's we just have to pull the purses in.

(Robert, 36 year old male, GBM, time two)

In some situations, such as retired individuals or those with no dependants, finances were not a worry,

Because I'm not married, because I haven't got any kids, so my financial side of things is comparatively simple.

(David, 48 year old male, GBM, time four)

8.6 Practical issues

Practical issues beyond dealing with finances that were reported as problematic tended to relate to travelling to the hospital and practical aspects of life such as organising treatment and care around other commitments.

8.6.1 Transport

Those patients who lived a distance from the hospital reported difficulties with travelling,

The most difficult thing for us on that sort of practical service level is that fact that we don't live round the corner from the <hospital>. So coming in from <town> or <town> is a drag, and I've only been here three times, and it's going to be a hellish drag if I have radiotherapy everyday.

(Hannah, 35 year old female, suspected glioma, time one)

The transport service was made available to patients who lived a distance from the hospital. However, this only applied to patients who were particularly unwell and needed assistance. Others made their own arrangements,

You know, so it was fine getting the transport and stuff and getting there in the morning. It was fine. Erm, I mean, the only hindrance is the fact that I'm living in [town] because of the train service sometimes.

(Ewan, 21 year old male, GBM, time three)

Use of hospital transport often meant a long and tiring day for patients,

It took us way round [town]. And all away around all these wee bits outside [town] and we never actually got back to [town] till half past five that night. And that was like being up from 7 o'clock in the morning. So that, that day, it knocked me back for about a week.

(Robert, 36 year old male, GBM, time two)

It rolled off my tongue initially, oh 6 weeks, I can do that. But, yes, I think, come week 5 I had really nearly had enough.

(Christine, 37 year old female, AA2, time three)

However, in many cases patients were grateful for the transport and willing to accept it,

It was the doctor who told me about the, the brain tumour, she was on, and she dealt with it then. And the next again day the transport was there. And I've never had a problem with it since then.

(Lois, 50 year old female, GBM, time three)

8.6.2 Parking

Parking within the hospital was reported by some as difficult,

I'm sure the biggest complaint of anybody coming to any hospital is parking. You know it's nightmare, this hospital.

(Hannah, 35 year old female, suspected glioma, time one)

The car park is atrocious. It's a nightmare for visitors to get parked.
(Betty, wife of Ron, 64 year old male, GBM, time two)

However, parking was not an issue that participants repeatedly mentioned as being problematic. Major changes to parking arrangements were made at the hospital during the study period which may have influenced perceptions.

8.7 Summary

People's personal, social and work lives were disrupted by the illness, meaning a number of adjustments had to be made. Complex and varied symptoms made leading a normal life very difficult. Patients had to deal with a loss of independence as they relied on those closest to them to assist them in activities of daily living. Moreover, people had to deal with the emotional turmoil associated with a glioma diagnosis and lived in fear of their tumour progressing and the inevitable decline this brought. Trying to regain features of their normal life was common among patients and carers alike, particularly for those not affected by profoundly disabling symptoms. Patients were willing to make changes in their lives in order to get back to life as it was, and were willing to accept 'almost normal' as part of the process of positive adjustment (returned to in chapter 11). In addition to dealing with the emotional and physical impact of living with a glioma, there were also financial and other practical and social implications. Some participants had concerns about their personal finances while others had passed retirement and the impact was less. People described difficulties in terms of knowing what benefits were available to them and applying for them. Transport to and from the hospital was also a significant practical issue.

Chapter nine: Death, dying and existential issues

As has been illustrated in chapter five, some participants were already considering death and dying before they had received a confirmed diagnosis. Fears of death appeared to be at the forefront of people's minds, whether or not they were articulated. However, there was a great deal of variation in awareness of the seriousness of their illness and the extent to which participants were willing to face and vocalise the possibility of death. In addition, each patient's illness journey was distinct and deterioration and closeness to death varied considerably from person to person. There were people in later interviews who were preoccupied with rebuilding their lives as outlined in chapter eight, and were able to suppress thoughts of death whereas others were declining rapidly and concerns around death and dying were all consuming.

9.1 Facing death

There was a varied attitude in the extent to which respondents were willing to vocalise their fear of dying in the interviews or to how they chose to position that fear in order to cope. An undercurrent of fears about death and dying were evident in the themes of distress, anxiety and worry in addition to uncertainty that have been addressed in previous chapters. Talk of death was not present in all interviews, either because participants had not considered it or I suspect because it was too distressing to talk about. Other participants were prepared to face the prospect of death head on, and began to discuss it from the time of our first interviews,

I'm not frightened of dying. And that's the easiest way to put it.
(William, 64 year old male, GBM, time two)

More commonly, participants discussed death with more trepidation,

I was scared when they telt me, when they said there was a tumour. It knocked me for six. I thought, oh my God, I'm gonna die, ken?

(Ian, 46 year old male, GBM, time one)

Conditions with the brain are more difficult to sort out. I thought to myself, oh God, don't tell me this is it, hey. [...] That was something that did worry me a wee bit.

(Angus, 59 year old male, GBM, time two)

Sharon feels that her husband Ian never did face up to the facts of his prognosis before his cognitive awareness deteriorated so far that it was too late,

So when we first got told that it was this kind of tumour, I was sort of saying, oh [patient] this is serious, you know, 'Och, I'll be fine, I'll be fine'. He never even got to, sort of, even contemplate that he wasnae going to survive this. By the time I knew that he wasnae going to survive it, it was too late because his head had gone then, you know.

(Sharon, wife of Ian, bereavement)

Patients commonly wondered about pain and discomfort at the end of life,

Actually, I would like to know what will happen nearer the end. I mean, I presume that I will be so drugged up that I won't know anything about it, but I don't know.

(Wilson, 58 year old male, GBM, time two)

I am fairly fatalistic about this whole thing. I'm also thinking this loss of independence. And also it is very natural, people think in terms of pain and stuff.

(David, 48 year old male, brain stem glioma, time two)

It is clear that there was still a great deal of uncertainty and unanswered questions for relatives also around dying and end of life care,

When it gets to the stage they cannae do anything else, what's gonna happen to [patient]? What does this tumour dae? Will it take, effect the brain? Your legs, hands, feet, talking and seeing. Cos it, if it starts to grow then it starts pushing your brain. That's the kind of questions I would ask, or that I would like answers to.

(Steven, husband of Lois, 50 year old female, GBM, time two)

I suppose thinking if the tumour came back and the diagnosis was really, there wasn't much they could do, which must be a realistic situation. Will he be alright? Will he be looked after? Will he have to go in a hospice? Will he be out of pain? Will he just generally be given as easy time as possible?

(Harry, father of Ewan, 21 year old male, GBM, time three)

Participants often had an acute fear of death at the beginning of their illness, which eases over time in many cases,

A: And I think we're beginning to be, well I am, less frightened of it.

H: Yep. I'm not, I have to say I am not frightened of it.

(Alice and Henry, 65 year old male, GBM, time three)

9.1.1 How long have I got?

Among those who were able to voice their concerns about death, a common pondering was the question: 'How long have I got?' regardless of participants' awareness of the prognosis for glioma. It seemed that this question was raised in people's minds right from the beginning and was often voiced in my early interviews with people when uncertainty was greatest,

I wanted to know, what, have I got 3 months, have I got 6 months, have I got a year? Or does anybody know? But they're not God, they can't, they can't tell us.

(Sarah, 66 year old female, suspected glioma, time one)

I thought, when this first all started, I thought I'm no gonna, she's 15, she's going to be 16 in June and I thought I'm no gonna see her be 16.

(Barbara, 45 year old female, oligodendroglioma, time two)

Concerns and uncertainty about life expectancy did endure in many cases and it was clear that it was on people's minds and causing some distress,

(Distressed) The main thing is, how long have I got left?

(Lois, 50 year old female, GBM, time three)

To be perfectly honest, part of my realism, I really, I didn't particularly expect to be alive at Christmas time. But it's strange, I feel in a limbo position er, because I'm sitting there, you know, months on from when I had this diagnosis.

(David, 48 year old male, brain stem glioma, time four)

9.1.2 Preparing for and accepting death

Participants' approach to talking about death and dying changed over time. An acceptance of the possibility of death became apparent.

Death became more salient as people deteriorated and it became clear they would not get better. As Sandy continued to deteriorate, three weeks before he died, he found it increasingly frustrating to the point where he did not want to go on,

I've kind of made up my mind that it's better to be going than live like this.

(Sandy, 47 year old male, GBM, time two)

Norman describes how he faced human mortality when he lost his first wife, which made accepting his wife's condition easier to come to terms with. Also, knowledge of prognosis from the start meant the expectation of death was there,

I suppose in a way, erm, knowing somebody is terminally ill makes it easier. I think also having lost my first wife, erm, you've, you've addressed your own mortality. Cos I think a lot of, very obviously from both, particularly when my first wife died, there were people around who, it dashed their hopes of living forever.

(Norman, husband of Winnie, bereavement)

For others, it took longer to make sense of what was happening and accept that death would come. Sheila took a long time to be able to face the possibility of losing her husband. In the end, he did have a good death,

He just shut his eyes and that was it. Everything just stopped. It was absolutely, so peaceful for him, I think.

(Sheila, wife of Andrew, bereavement)

It was only with the passage of time that some participants could talk about the unspoken knowledge of prognosis,

Although I said that we didnae want to tell her, I think myself, she knew.
(*Jim, husband of Mary, bereavement*)

People experienced a series of losses from the time of initial diagnosis. As their loved ones deteriorated, some people felt they were grieving for their loved one before they had died,

But she said erm, you're doing your grieving now. Erm, and that was one of the best things somebody said to me because I said, right enough, from when we were, we've had the diagnosis, that's when the grieving started. It was so painful, you'd lie in bed at night, cos obviously he was in hospital at that time, and you'd say, I'm going to be in this bed on my own.
(*Audrey, wife of Bill, 63 year old patient with a GBM, time four*)

Ewan's father describes how hearing the diagnosis and knowing the prognosis from the start is the biggest loss he experienced,

But, you know, in terms of how it affected me, I think it was almost worse when he was first diagnosed way back in August '06 because his, being a young man, his life ahead of him just being removed. And that was the heartbreaking point, heartbreaking. And it was a huge, huge shock. Whereas when he eventually passed away this year, he had been through a lot. And he knew he didn't really have a future at all, and so did we.
(*Harry, father of Ewan, bereavement*)

Sharon describes the grieving process as more of a defense mechanism to help them deal with the loss of their loved when they do die,

I'm quite pragmatic and start to think, I think I started detaching myself quite early on last year, you know. It's like, you know, och you cannae prepare yourself for it or anything, but it's like, it probably helped that his personality did change because I had got to one point in May/June and I sort of thought to myself, you know, even if he beats this, if he gets better, the tumour goes away, but if he is left with that personality, I don't think I could stay. I couldnae put myself or the kids through that. So, you know, it was maybe a blessing that what happened happened, I don't know.
(*Sharon, wife of Ian, bereavement*)

Julie, on the other hand, did not have time to prepare for her husband's death, because it happened so quickly,

I did nae think it would be as quick. I mean, from basically the diagnosis in the middle of October, it was not even 12 weeks. And that's unbelievable.

(Julie, wife of Sandy, bereavement)

9.2 Getting affairs in order

Part of the process of preparing for death is an overwhelming need expressed by patients in particular to 'get one's affairs in order'. Again, this theme is evident from the early interviews when patients' lives were first threatened. A part of this is concern for loved ones left behind,

But erm, my main concern's been for ma wife and family. You know, I've got a lad there at 17, I need to spend a bit o time wi and get his confidence levels up. The other two are no too bad. But erm, I've got a bit o work to do with him yet before I can abdicate my responsibilities.

(Sandy, 47 year old male, suspected glioma, time one)

I've got time to put my affairs in order. Erm, my wife and family are the ones who are going to suffer.

(Wilson, 58 year old male, GBM, time two)

There were often practical implications to ensuring loved ones were provided for,

We went and seen the lawyer and we've been doing everything from our side to get everything, like our house, so that if anything happens to me automatically goes to [carer]. Like money in the bank and things like that.

(Robert, 36 year old male, GBM, time two)

I've been pottering around doing financial stuff and as I say this lawyer thing this week. I don't want to leave my sister in the position of like, as I say, [inaudible] I've got to organise that.

(David, 48 year old male, brain stem glioma, time two)

Also evident is the need to organise finances and de-cluttering and getting one's house in order,

Erm, I suppose that er getting, tidying up the paperwork and just being sure that er, [carer] is taken care of and that er we arrange things so that the tax man doesn't get too much of it. These have become important things. [...] Having got the, the fright and having got the time it gives you a bit of a chance to get your affairs in order.

(Henry, 65 year old male, GBM, time three)

Well I mean when there's lots of things to be done and you think oh gosh I should be doing them. You go out and I'm cutting the grass and I'm saying that's needing weeded when can I get that done you know, it's a time thing I want to get that done.

(Bill, 63 year old male, GBM, time three)

9.3 Preferred place of care

This was a discussion that not many participants were willing to broach in interviews.

For those who were willing to discuss their preferred place of care, there was a diversity of thoughts. Patients themselves were concerned about being a burden to their loved ones if they were at home,

You don't know how this deterioration ends up, how bad it might be or whatever. You know, because I don't want to, you know, become a, a complete burden on my sister.

(David, 48 year old male, brain stem glioma, time four)

Relatives considered both their own and the patients' needs,

I would struggle if he was here all the time and you know, even although people may come in every day. I don't know what the options are. I don't know. I just want to know that something would be in place for him to help him if that was gonna happen.

(Harry, father of Ewan, 21 year old male, GBM, time three)

But the way she was in the hospital, to the extent they had to use that crane thing to lift her out of bed and lift her back in again, she thought we could get one of them in the house. And I said, [patient] there is just no way. I says, well myself, I just couldnae do it. So she was in the best place at that time.

(Jim, husband of Mary, bereavement)

It was also clear that most patients and carers lacked information about practical aspects and options for their care in the last weeks or days of life.

In an extra interview to capture the end of Bill's life, Audrey talked about why it was so important to keep Bill at home,

I think because erm, er, mebbe it won't be so good now, but the times that erm, he was aware and erm, er, able to speak, erm, I was here. Whereas if he'd been in hospital I might have missed those times.[...] I'm here all the time so I was always getting any good bits that were going.

(Audrey, wife of Bill, 63 year old male, GBM, time five)

Certain participants were much more closed on this subject and in hindsight it was insensitive to have raised this question in this particular interview,

That's too far away for me. Don't know. But we've never looked, we've never spoke of what's in front of us yet.

(Lois, 50 year old female, GBM, time three)

9.4 Palliative care

In most cases, there was little or no discussion of the involvement of palliative care services in the early interviews except in a small number of cases where the patient was particularly ill. As time went on, participants became more involved with palliative care services. Participants recognised the association between palliative care and imminent death and were keen to dispel the link,

Everybody thinks [hospice name] and hospice and that's it, you go there to die, you know. But it is no like that. [...] You can go up for a massage, everything you want. [...] They know more about the medication than like the doctors do you know, because they are trying to deal with everything eh. Whereas the girls, the girls up there they are sort of specialised in what they need.

(Andrew, 45 year old male, GBM, time three)

There was still some degree of resistance to the involvement of palliative care services,

The local doctor suggested to me, perhaps a visit from, you know, the local hospice, [hospice] and see what perhaps they could do for me. [...] I mean, that's something I'm kind of reluctant to do, particularly involve myself in.

(David, 48 year old male, brain stem glioma, time four)

The nurse from the hospice did suggest that he could go into the hospice for a few days to get the medication sorted out. [...] Erm, but you're always frightened that if they go in for a few days, they don't come out again.

(Audrey, wife of Bill, 63 year old male, GBM, time five)

However, the input offered by these services was valued,

They have a hospice, [hospice], there has been a sister over there to visit me and tell me about, I can go into the day centre for a day if I wanted to go. And if the need ever be that I need to go in, then I can go into the [hospice]. And it's a nice place and the people are very nice, the staff in there are excellent.

(William, 64 year old male, GBM, time three)

This is at the Macmillan centre yes. It really is excellent [interviewer], it's lovely. And I'm awful glad that I went.

(Deirdre, 56 year old female, GBM, time three)

Sharon was impressed with the support they got from community palliative care services early on in Ian's illness,

The fact that, actually, you know, like the MacMillan nurses and she arranged the woman from Crossroads to come out and things like that. I mean, they were there right from the beginning. So you do have that, you know, that security.

(Sharon, wife of Ian, 46 year old male, GBM, time three)

Although it was difficult to capture end of life issues prospectively, relatives described the end of life period in bereavement interviews,

So, he was in hospital and he was in hospital for at least, about a fortnight I think. And very immobile and hardly able to get out of bed at all. So things were deteriorating. And they suggested he was transferred to a hospice.

(Harry, father of Ewan, bereavement)

Ewan's GP also became more involved in coordinating end of life care and helping make decisions with specialist input from the hospice.

Sharon was very happy with her husband's end of life care in the hospice,

They couldnae have been nicer, really. [...] You know, treated him with a lot of dignity. I think, cos he was a lot younger than what they were used to, you know, it was a bit difficult for them. And you know, the kids were young and stuff like that.

(Sharon, wife of Ian, bereavement)

Others were able to care for their loved one at home with help from the community team,

Eventually we got home and that was the best thing, was us just coming home. Because then [patient] was here and er, everything just fell into place after that. You know, got the help and everything at home. [...] The nurses were fantastic, they were from the [GP practice]. They came up twice a day anyway and then I had night time ones coming in. Which - they were all lovely as well. [...] It was really special, yeah. It was, it was good memories. It just meant the boys could spend time with him as well.

(Sheila, wife of Andrew, bereavement)

However, care was not always satisfactory. In the case of Sandy, his deterioration was so quick and unexpected that his family had been struggling to care for him at home with minimal input until it was too late,

It was quite good that he was here and he wasnae back in the hospital. But a MacMillan nurse came out the week, he died on the Tuesday, she came on the Friday morning. She says I think what we're needing to arrange is for a nurse to come in during the night.[...] Cos we were up all night wi him cos I don't think, he'd lost track of time and didnae know if it was day or night. So anyway, the MacMillan nurse, she says no, you'll need to get some help in cos this, you know, yous are all gonna make yourselves ill. Er, and the MacMillan nurse came in on 1st January, she came at 7 o'clock at night, and that was the night before he died.

(Julie, wife of Sandy, bereavement)

9.5 Spiritual and existential concerns

‘Spirituality’ was not something that participants reported as high on their agendas unless they had a religious faith, which was the most common interpretation of spirituality. However, upon closer inspection, narratives surrounding existential concerns *were* evident from the time of first interviews. Taking information on board about diagnosis and prognosis and trying to deal with and make sense of it posed some of the ‘bigger’ questions in life, and people became more contemplative,

S: Erm, no as I say, I was looking for answers and I haven’t got any. Y’know, I’ve tried to get answers to some of my questions and it hasn’t come yet.

[..]

S: I actually went and sat in that chapel, I must have sat there for a good hour and I read the bible. And, like I say, I am *not* a religious type person at all, you know. But it was just so peace, it was quiet, it was peaceful.

I: And what were you thinking about while you were there?

S: What was gonna happen? Life. What about the kids? Will I dance at my grand kids weddings? Mmmm.

(Sarah, 66 year old female, suspected glioma, time one)

Others did not have a conventional religious faith, but found comfort in other ways,

I would say, really, what’s got me through this is more being, I’ve had faith in the medical profession more. More more than er, that has, has taken me through. Uh huh. More than a spiritual side, you know.

(Ann, 66 year old female, suspected GBM, time one)

David found a kind of spiritual fulfillment through his love of art,

I source my kind of spirituality and beauty for me is through art. And again it is not in any way a religious thing at all. I mean I’m not religious in the slightest. But er, and it’s not that I’m particularly at this time, you know, feeling more strongly spiritual, but as I say, I just get pleasure erm and erm, Just the beauty of objects and things like that. So I think that maybe is reflecting you know, I mean I am probably doing more of that.

(David, 48 year old male, brain stem glioma, time three)

Some people found themselves turning to their spiritual side to help them cope,

You can find yourself getting quite spiritual in situations like this too though. I think you're feeling a bit more desperate though and very vulnerable.

(Sandra, 46 year old female, suspected glioma, time one)

You know I've been praying myself. (laughs) Just that everything will, what's gonna be is gonna be, but hopefully it will be a positive outcome for us all.

(Julie, wife of Sandy, 47 year old male, suspected glioma, time one)

9.5.1 Religious faith

There were a small number of participants who actively practised a religious faith.

Religion was able to provide a comfort for those who had faith in God,

I believe there's life after death. That er... so that way I'm not frightened of dying. I'm quite happy to, to... And I... it calms me down. I know whatever happens, when it happens, will be the Lord's decision, not mine.

(William, 64 year old male, GBM, time two)

I'm not afraid of dying really and it's because of my faith you know, [...] it gives me you know a comfort, a peace.

(Bill, 63 year old male, GBM, time three)

The church provided spiritual comfort but was also an important source of social and emotional support for people, which they valued greatly,

There's a great erm, erm, boost from all these different people plus the fact of the, the people in [town] that go to the church in our part of the community there, I mean, they're very, very supportive.

(Audrey, wife of Bill, 63 year old male, GBM, time four)

For others, their experience strengthened their faith as they came out of the other side of a difficult time,

It's when you can come out the other side of it and think, no I'm gonna get there. And for me there was never a doubt, it's, it definitely helped my faith. [...] In fact it's given me an insight as to how precious life is. Really.

(Deirdre, 56 year old female, GBM, time three)

However, in Deirdre's situation, she appeared not to be aware of her prognosis and to an extent had a 'blind' faith that everything would be okay. It was not clear whether this was a form of disavowal in order for her to cope.

Many participants do not feel that religion or any spirituality has anything to offer them and dismissed the idea of being 'spiritual' in any way,

When I was walking along the, up the <hospital>. I used to walk past this wee chaplaincy. And I just thought it's pointless because I'd never go any other time. There's no point.
(Andrew, 45 year old male, suspected glioma, time one)

I think if you were of that type, it would be quite a erm, comfort if that's the right word. [...]I haven't really thought of that yet. It may come eventually.
(Angus, 59 year old male, GBM, time two)

9.5.2 Why me?

As participants struggled to make sense of their illness, many questioned why this should happen to them. There was a feeling of being cheated,

All I could think of was you know, we've looked forward for years and years to the two of us retiring together. I don't know how much longer we've got together, but erm, er, it looks as if that's pretty much exploded now.
(James, husband of Sarah, 66 year old female, suspected glioma, time one)

B: That's what I mean you know, I was really annoyed that this should happen to me, you know how you say well why me? ...

A: So that's that's sort of boosts you a wee bit to realise that um, you have got a wee bit. But still, you just feel a bit cheated when you're only 63.
(Bill and Audrey, 63 year old male, GBM, time two)

On the other hand, William made his peace with why God had allowed this to happen to him,

And you look up and just say right...The lord suffered more than I will ever suffer. And... why should it happen just to him when it could happen to a lot more people? And that's it, makes me appreciate what he did.

(William, 64 year old male, GBM, time two)

For others, previous experience had changed their thinking on fate and the control they have over it,

Wi my mother, I thought why my mother? You know, 37, that's a shocker. Er, 5 youngsters. And then wi wee [son], wee [son] got about 5 month. Aye, I don't think that now. I didnae get an answer to it then did I?

(Sandy, 47 year old male, suspected glioma, time one)

I think I told you about my friend who [had the brain hemorrhage] I mean, he'd had headaches for a long time and they hadn't been diagnosed, well, so why me? Was particularly pertinent because, you know, I lived and he didn't. So I have always thought that if it, you know, what will be, will be. Que sera sera.

(Wilson, 58 year old male, GBM, time four)

As time passes, there was a change in thinking as people accepted their situation,

...And then you say well why not me. Somebody's, people get ill that's it that's life. I'm doing better with myself with accepting it

(Bill, 63 year old male, GBM, time three)

I think maybe that's partly why I am fairly pragmatic about, you know, this aspect of, you know, life and death. I don't think any of us are special. Everyone is as important as everyone else. But ultimately we're all insignificant is really how I regard it.

(David, 48 year old male, brain stem glioma, time four)

Some participants stopped questioning 'why me?' and saw it as a fruitless task,

Now I've, don't get me wrong, I'd still like to say why me, I've been through rather a lot with my accidents and things, but what's the point? It is me now, so deal with it and get on with it.

(Christine, 37 year old female, low-grade glioma, time three)

I don't really, I don't really see the point of the why me? The why me bit, is wrong because it kind of implies you wish it was someone else. I wouldn't wish it for someone else.

(Henry, 65 year old male, GBM, time three)

9.5.3 Philosophy on life

Narratives surrounding approach to life emerged in interviews. Participants reported some changes in the way they thought about their lives,

Much more appreciative. I'm taking each day and I'm enjoying it. That's my attitude now, be a bit more positive not be so grumpy. [...] A bit contemplative at times, thinking about things that I wouldn't normally you know, think about the future in a different way.

(Bill, 63 year old male, GBM, time two)

I just, it brings it all into focus. You begin to appreciate people round about you and you're not so self-centred.[...] Heightened awareness of emotions, heightened awareness of relationships. It stops you just going on with life as, you know, as normal.

(Harry, father of Ewan, 21 year old male, GB, time three)

9.5.3.1 Making the most of time you have

A strong theme emergent in relation to talk about approach to life was for people to make the most of the time they had,

I had a friend who went to bed with a headache, erm, in the summer, August, and never woke up again because he had a brain tumour. I've been given a vast opportunity that he never had and I intend to use it.

(Wilson, 58 year old male, GBM, time two)

After the initial fear of dying at the time of diagnosis, having more time was valued by participants and they appeared to feel more vital,

Every day is a bonus. And you wake up in the morning and say well, I've got another day ken? [...] You look at life and you think, 'Yes'.

(Ian, 46 year old male, GBM, time two)

Patients were keen to stay in the moment and appreciate the life they had while contemplating the beauty of the world around them,

You know I enjoy it, you know I love it here, it's wild. But erm, I enjoy walking the dog.(distressed) I like to get away because I can show you where the buzzards are nesting and you know. I've seen more deer roond about here this year than I've seen rabbits. You know, and there's heron in the burn and different things.
(Sandy, 47 year old male, suspected glioma, time one)

I get up early now and I like to look out at the day break you know and see the sun coming out over there it's good, I enjoy that. And I think well what's today going to bring? Nice and quiet and have my thoughts and think that's nice that's, life could be a lot worse, yeah. Just thinking what a wonderful world you know.
(Bill, 63 year old male, GBM, time three)

9.5.3.2 Shifting priorities

Facing a life-limiting illness led many participants to adjust their priorities in life,

Ken, I'm looking here and I'm thinking what are we pushing for all of the time, ken? Sometimes you should actually just sit back and enjoy what you've got and relax... So I think that's my kind of motto now, like.
(Robert, 37 year old male, GBM, time two)

I mean, we have had to face our own mortality probably earlier than a lot of people have to. But from then you just build up on it. It has changed our outlook on life. And made us, you know, more positive and enjoy things more.
(Angie, wife of Wilson, 58 year old male, GBM, time four)

For Malcolm and Joan, they felt they already had their priorities in order but certain sentiments were reaffirmed,

Living in today has not changed, but for me perhaps, I find it, I knew it was important, but now it is essential.
(Joan, wife of Malcolm, 41 year old male, AA3, time two)

However, a small number of participants didn't feel that they had changed the way they approached life. Ewan suggested he waited for an epiphany that never came,

Erm, well I suppose people on TV and stuff always kind of, get this lust for life thing. Erm, but I don't think I have that really, I don't think it's changed me all that much, or at all.
(Ewan, 21 year old male, GBM, time four)

9.5.3.3 Orientation to the future

In relation to the theme of shifting priorities, participants showed evidence of changing the way they thought about their future,

I'm no even gonna lift my head up to look forward to the future, I'm just gonna take it as it comes ken? Just if it hits me, it hits me and that's it.
(Adam, 28 year old male, AA2, time two)

You tend no to think too much in the future anyway cos you are only sort of looking to the near future. Erm and hoping you are going to be there to see it eh.
(Andrew, 45 year old male, GBM, time three)

On the other hand, there were practical steps that needed to be taken, meaning that the future was put back on the agenda,

Well for instance we've never made wills and we're going to do that now, you know. So we are facing all those things. You know, things like that, we've, I suppose we've got a bit more sensible.
(Angie, wife of Wilson, 58 year old, GBM, time three)

Others saw it as a separation of practical and emotional aspects of the future,

I've tried to live in the day, that doesn't mean that I'm not organising the future a bit. In many case like studying and, and financial cases I obviously have to organise it a bit. But that's not a problem. But trying to live in the future is different, it's not the same as organising the future.
(Malcolm, 41 year old male, AA3, time two)

9.6 Dealing with the loss of a loved one after death

The coping strategies used by bereaved carers closely mirrored those used by patients and carers in dealing with a diagnosis of glioma.

9.6.1 Feeling lost or isolated

After a loved one was gone, there was a feeling of isolation and loneliness among bereaved carers. People described feeling lost or 'at sea' and not sure what to do with themselves, often after many years of marriage,

59 year was a long time. That's it dear, I cannae say any mair. It's just bringing it all back.
(*Jim, husband of Mary, bereavement*)

It's not the way it's meant to be eh? And I just feel lost. [...] I just feel really lonely, you just don't know what to do with yourself.
(*Sheila, wife of Andrew, bereavement*)

Shauna describes how she feels socially isolated and lacking in support from those around her,

The week that he died and the week after it, there was always somebody in to see me. And they just don't seem to be coming now.
(*Shauna, wife of William, bereavement*)

9.6.2 Getting on with life

Resuming activities and other aspects of normal life was very difficult,

It's not the same. It's not the same going without him. (Distressed) Sorry.
(*Julie, wife of Sandy, bereavement*)

We always went round as a couple. And all of a sudden I am on my own. I never used to take the keys or the money, I just used to get in the car and go. Get dressed and go. Where now I

have to make sure, I've got the car to myself now, I've to make sure that you know, I've got petrol in the car and keys and everything.

(Sheila, wife of Andrew, bereavement)

For others doing some of the things they had done before was comforting and a source of support,

Well [friend] I says, we're going oot next week and I'm no taking no for an answer. So we went oot, but then [friend] went on holiday and [other friend] went on holidays. But I'll give them a phone and we can go oot next week again. Cos it does help just to get away for a wee while.

(Shauna, wife of Bill, bereavement)

9.6.3 Keeping busy

In order to cope with the loss of their loved one, keeping busy and having a focus was very important. This often involved a change in role and identity for many as they adjusted to life after their loved one was gone. For Shauna it was spending time out in the garden, a new hobby. For Audrey it was meeting friends for coffee and staying out of the house for longer, when previously she would have returned home with Bill. Julie found work a welcome distraction. Norman described having a focus as helping him to deal with his loss,

So I'm just planning to go somewhere every month at the moment, to go and visit people. Erm, which gives you a focus of something you're going to do. [...] It's filling the gaps at the moment, that's really the way of life.

(Norman, wife of Winnie, bereavement)

Sheila tried to keep busy but finds it difficult to face the world on her own,

Just keep myself busy. I don't like really going out the house really. But I do. Do you know what I mean, I do. I get all panicky and all worked up and everything, but then when I am out in the car for 5 minutes, then I sort of calm down again.

(Sheila, wife of Sandy, bereavement)

9.7 Summary

Concerns around death and dying were present in participant accounts from the earliest interviews before a confirmed diagnosis had been made. Fear of dying was acute around this time and often appeared to be suppressed as people found it too difficult to voice. As time passed, fears did ease and people were more able to talk about and reflect on their concerns. Patients wanted to know whether or not they would be in any pain and relatives said they would have valued more information on what to expect so that they could be prepared and care for their loved ones. Patients wanted to use the time they had left to organise their affairs so that their loved ones would be provided for. Patients were not forthcoming in talking about where they would like to be cared for and the issue was not raised independently by relatives until such time as the patient began to deteriorate. Participants were very satisfied with specialist palliative care services and made use of the day hospice and in-patient care during the course of the illness. Participants did not immediately recognise existential needs but discussed a range of concerns around their mortality, expectations from life and appreciation of relationships and their surroundings. People's priorities in life and orientation to the future also changed. Bereaved relatives employed similar coping strategies to those used during the course of the illness to deal with the loss of their loved ones.

Chapter Ten: Health professionals' views of glioma services

GPs' and other health, health-related and social care professionals' views on the provision of services for people with a diagnosis of glioma identified a number of issues and areas for improved care. The integrated perceptions of those interviewed, combined with findings from all results chapters, went on to inform a number of recommendations presented in the conclusions chapter.

10.1 Hospital services

Hospital staff believed that the services offered to patients were good overall,

From start to finish, no I think, I don't, I can't imagine that there would be any barriers for them. I think it is a pretty open and honest service that is provided.

(Charge nurse, oncology)

I think patients, they have been given a very good service here. They get seen on time, they get treated on time. We get the op at short notice, they have their scans reviewed very quickly.

(Specialist registrar, neuro-oncology)

However, they identified issues affecting the efficient running of neuro-oncology services. For example, diagnosis was not handled as effectively as the surgical team would like,

The difficulties with the timing are that the surgeons have a lot of contact with people before their operation and immediately after their operation. However, the vast majority of people are discharged long before we know what the exact diagnosis is. So these people are then confronted with coming up to a clinic to meet people who they have never met before, to get some of the worst news possible.

(Consultant neurosurgeon)

Delays in discharge home were also a problem in complex cases,

There's also a phenomenal delay in discharges because we're waiting for social work input and then even getting packages of care, there's a delay in the community. And I would say it may be particularly relevant for this group of patients who often need a lot of social services.

(Consultant in palliative medicine 2, hospital-based)

For those living some distance from the hospital, travel for appointments was perceived to be a problem, with implications for more shared care and follow-up in the community,

I think we are trying to, well we are repatriating most of the patients down to [town] because it is an awful long way.

(Consultant in palliative medicine 1, regional hospital-based)

Lack of resources was a common problem cited by many professionals, including transport issues, manpower, and bed space,

Limited time and resources is the biggest challenge that we face.

(Clinical psychologist)

There is no funded oncology speech and language therapy service at all.

(Speech and language therapist)

Patients had to live with a social disability such as dysphasia as well as many other impairments because the services were not available or appropriately geared towards patients with a limited prognosis in order to help them manage it.

Emphasis in hospital services was on clinical care, with less emphasis on psychosocial care and support,

When we first meet people, you know, we have one consultation and there is a lot of ground to cover. We tend to be very focused on the treatment because that is what we have to organise next. [...] So we don't always have the time to sit down and sort of, explore how the patient is dealing with their diagnosis.

(Consultant oncologist 1)

I think it's still very much linked into the medical model.
(Hospital chaplain 1)

While health professionals did recognise psychosocial issues associated with a brain tumour diagnosis, they did not feel these issues were being adequately addressed in the hospital setting.

10.1.1 Specialist nurse service

Specialist nurses offered expertise in the management of patient care on issues such as medication as well as an intimate understanding of the range of psychosocial issues affecting patients. The nurse specialist role was central to coordinating patient care,

The liaison with the community is the key thing in these jobs. It really should be called a liaison post.
(Neuro-oncology specialist nurse 2)

The key person, not locally, is [specialist nurse]. Definitely. And the patients see her as the key person.
(Community palliative care nurse 4)

However, they encountered some resistance from the neurosurgical team,

Apart from anything else, the neurosurgical team, the idea of CNS they not entirely sold on. They're not all believers.
(Neuro-oncology specialist nurse 1)

Furthermore, because of the timing of confirmed diagnosis, patients were often not aware, preventing the nurse specialist from providing appropriate support at this time,

There's nothing that indicates that they do know exactly what the diagnosis is. So then it is very difficult for her to be involved early.
(Nurse practitioner)

There was concern about the heavy reliance on the specialist nurse,

I think, because we use [specialist nurse] so much we probably over rely on her to be honest. If [specialist nurse] wasn't there then we would have to know all these things.

(Charge nurse, oncology)

So clinically as a service, we do very well, but sort of, from the emotional and spiritual needs of patients, I think on a neurosurgical basis we don't do well, at all. And we put it all on the shoulders of our neuro-oncology specialist nurse, [nurse].

(Nurse practitioner, neurosurgery)

10.2 Primary Care Services

GPs reported variable involvement while nurses working in the community played an important role in caring for brain tumour patients. District and community specialist palliative care nurses were also central to patient care, particularly once active treatment was over.

10.2.1 GP Involvement

GPs talked about the different components of their role and how it shifted and changed as patients progressed through their diagnosis, treatment, follow-up and in some cases recurrence and terminal care till death. In some cases, care was shared with more than one GP whereas other practices had personal lists to ensure continuity of care with a named GP. There was a wide variation and debate about GPs' involvement in patients' care, based on differences in perception of what involvement should be, patients' wishes, stage of illness, and care needs,

We're general physicians, you know, we're here for, if he gets something else. You know, if he gets ill in the meantime, if he gets a chest infection or if he gets, you know, some other medical condition, diabetes or something, then yeah, our job is find that out and check that out, you

know. But really, you know, we're not, we just don't have the specialist knowledge, I don't think, in a case like that, to really be of a great deal of use, you know.

(GP of David, 48 year old male, brain stem glioma)

Others felt GPs were in the best position to oversee care as a generalist,

They never got to the point of realising that, in fact, it is nothing to do with specialism. Once you have had the diagnosis and a bit of treatment you don't need to be there. And probably shouldn't be there. [...] And realise that actually all that they're needing is care. And care actually comes from GP waffling, nurses coddling. And not from whacking great doses of medicines that are MRI scan images.

(GP of Winnie, 59 year old female, GBM)

It was sometimes assumed that the specialist centre were responsible for care and the onus was on patients to seek help if needed,

But I suppose we rely on them to come and see us to let us know if they're experiencing problems. Erm, and you know, I mean, I think, er, we assume, perhaps wrongly or rightly, I don't know, that the hospital has a fairly good back-up for people with brain tumours. We're pragmatic, we don't run around looking for work.

(GP of David, 48 year old male, brain stem glioma)

On the whole, there was balance to be struck and patients' wishes were respected,

Erm, it's always difficult this, erm, knowing how much to intervene. Erm, but what I've tried to do is to make sure that people know where I am and how to get hold of me and you know, to be available to them. But not to be intrusive either. And you know, trying to over medicalise the situation. But, you know, really they probably want to spend some time getting on with their lives.

(GP of Henry, 65 year old male, GBM)

10.2.1.1 Diagnosis

There was a real variation in GPs' involvement in diagnosis depending on the route patients underwent. In cases where the patient presented as an emergency, the role of the GP at this time was redundant,

I didn't have any role actually, to be fair. He was admitted acutely through the local casualty department, having presented with a seizure.

(GP of Robert, 36 year old male, GBM)

Well he didn't present to me at all. He had a fit while driving, crashed his car and was taken to A&E.

(GP of Wilson, 58 year old male, GBM)

GPs played a more integral role in investigation of symptoms and referral onwards when patients had a slower path to diagnosis, such as patients with a low-grade tumour where a pattern of complex symptoms unfolded over time, prompting referral. In other cases again, patients had a referral in process that was overtaken by an emergency admission. For example,

I think I did an urgent referral to the er, neurologist or neurosurgeons[...] because of her presentation, and erm, I think before she was seen, she was actually then admitted to hospital because she deteriorated.

(GP of Deirdre, 56 year old female, GBM)

I had referred him to [hospital]. But events overtook that and he was admitted as an emergency over the subsequent weekend.

(GP of Henry, 65 year old male, GBM)

10.2.1.2 Follow-up, monitoring and coordinating care

GPs described their role as multi-faceted,

Mainly the follow-up. You know, how she's doing after the operation. Erm, on the medication for the ongoing review and the treatment of some symptoms like headaches, you know. What we call contact care review, erm, just to make sure they are aware of the diagnosis and discuss treatment.

(GP of Deirdre, 56 year old female, GBM)

Even when there aren't any symptoms, I try to check in a couple of times a week as well, just to make sure that things are kind of, stable and OK.

(GP of Bill, 63 year old male, GBM)

10.2.1.3 Symptom control

GPs also had a role to play with hands on medical care,

Explaining tablets he was on. [...] You know, and reviewing medication. I actually had to readmit [patient], I had some concerns that his seizure activity, which was kind of, after that, had been increasing.

(GP of Robert, 36 year old male, GBM)

More laterally erm, the involvement has been with a lot of symptom control. So, morning headaches, vomiting erm, and agitation, particularly at night time has been a problem as well.

(GP of Bill, 63 year old male, GBM)

Coordinating symptom control also required liaison with specialists in palliative care,

If you have a problem, there is then the hospice doctors, because they are more dealing with the pain management than erm, than us.

(GP of Sandy, 47 year old male, GBM)

10.2.2 GP Skills

All GPs commented on how rarely they had cases of glioma in their career. While GPs felt they were more familiar with the trajectory of breast or lung cancer, for example, they were not so confident in managing primary brain tumours, particularly symptom control,

And what I've learnt about glioma really has been told by [patient]. And she brought me the leaflets she'd been given. Er, so I read that as well.

(GP of Barbara, 45 year old female, low-grade glioma)

And I don't think we are particularly equipped to go out and discuss the ins and outs of secondary chemotherapy. [...] I couldn't tell him what the chemo would be. You know, what the side effects would be and how, what the chances were.

(GP of Ian, 46 year old male, GBM)

Community palliative care specialists were a source of advice,

I have spoken to one of the doctors and [hospice], not on this occasion, but last year, about erm, medication. Erm, I think they went up to see them because I was, you know, felt out of my depth a bit on that particular item. [...] They are there as a resource to you.

(GP of Andrew, 45 year old male, GBM)

GPs endorsed a guide for health professionals to refresh their memories about management of primary brain tumours,

As a GP, sometimes the number of brain tumours you're going to see is going to be very few. What might be quite useful is if you could get some guide or something like this. If somebody had a diagnosis like this, what you then might expect [...] to happen.

(second GP of David, 48 year old male, brain stem glioma)

Elsewhere, a more formal email system was suggested as a way of liaising with specialists,

Erm, the renal unit in [town], erm, have email advice, that sort of thing. That was incredibly helpful. Was telling me lots of medical things in a totally unpatronising way. [...] You know, it was almost like having a renal, you know, a friendly renal consultant in your back pocket. [...] So I think, email advice is, is good. [...] It needs to be resourced properly and lots of people contributing I suppose, so that there's cover at all times. It's all about communication as far as I see it.

(GP of Barbara, 45 year old female, low-grade glioma)

10.3 Shift from secondary to primary and community care

There was a strong sense among professionals that the emphasis on whom coordinated care underwent a shift as the active treatment phase ended. Patients' needs changed over the course of their illness and on a case by case basis,

Different at different stages I would say. [...] And different people are different in each case. It might be the hospice in one spectrum, it might be, you know, the surgeons at the other end.

(GP of Lois, 50 year old female, GBM)

GPs' involvement often increased after active treatment was over,

My involvement picked up with him when he was discharged back locally.
(GP of Robert, 36 year old male, GBM)

Well obviously if it becomes terminal, you know, we'll obviously be in a position to help, you know, [...] we really would be becoming involved. [...] We would normally get the local palliative team, the care team involved. [...] As long as there is no sign of any recurrence, you know, I am quite happy with just to carry on with whatever [patient] wishes.
(GP of Wilson, 58 year old male, GBM)

There was a perception of lack of consensus over who should coordinate care,

I think the difficulty for community teams is knowing who's coordinating that service. Our, really, we see the GP as the leader in that service. But GPs often don't see that as being their role. [...] I think it's that they feel out of their depth and they don't have the knowledge required. [...] There needs to be more support in the community for patients. I don't think more hospital-based support is the answer.
(Neuro-oncology nurse specialist 2)

Obviously after they have finished their radiotherapy, their contact at the hospital may go down to once every few months. So it is important that the people in the community have a good idea as to what the current problems are, the current management, so they can continue with that.
(Consultant oncologist 1)

Versus the community-based perspective of resistance from hospitals to hand over care,

These hospital people think they're supreme, you know, they are better than the community workers. The community is dumb, dumb people. You know, GPs are OK but the hospital doctors, of course, they know their job. They are supposed to tell the, they don't understand, how long have we been in somebody's house. They don't know how the extended family works, they don't know how the care works. They are good in making acute diagnosis, they are not really good in chronic care, you know. [...] I think this thing has to be removed, you know, that hierarchy of the hospital to the community.
(GP of Sandy, 47 year old male, GBM)

Or do they all go up and see [nurse]? Is [nurse] super nurse, you know? There are community people who could support these people. [...] It is about informing and believing that the local team can give care.
(Community palliative care nurse 5)

There was concern that a gap in care could develop and patients ‘fall through the net’,

Well that’s difficult isn’t it? I mean, the worry that you have with these people is if they fall in between stools. [...]I mean, I think, in this case, the key player is the patient.[...][Patient] are both intelligent people who erm, can often sort that sort of thing out for themselves, but not everybody is the same as that. And not everybody is as confident in dealing with professionals.
(GP of Henry, 65 year old male, GBM)

The overriding impression from all of those interviewed was that a greater emphasis was needed on community-based follow-up and support, despite concerns voiced about lack of specialist skill.

10.3.1 Improving coordination and continuity of provision

A key coordinator to advocate for the patient and pool all the services together was recommended to ensure continuous, effective and efficient communication and care,

I do think there is a point which we need to go to somebody and it doesn’t have to be the GP. And it tends to be in this building. It could be the [centre], there is no, it’s not a medical one but they need to know where they are going to and then branch from there like spokes of a wheel. Rather than meandering round a system.
(GP of Winnie, 59 year old female, GBM)

There are obviously, there’s MacMillan nurses, there’s district nurses, there’s liaison nurses, there are intermittent hospital clinic outpatient appointments. Often it’s a different person seen at each of them. So at least I have the, the kind of, consistency of being there and overseeing the whole thing, really, just to smooth out some of the rough edges.
(GP of Harriet, 64 year old female, GBM)

A specialist nurse working at the interface between hospital and community care was suggested,

Maybe one, erm, responsible person who could co-ordinate it. With the GP, of course, it is just too general. Erm, but like in heart failure, there’s a dedicated heart failure nurse. And lung cancer, I’m sure there is a dedicated lung cancer nurse er, who can maybe pull those strings a bit

together, you know [...] It is like a kind of outreach where there is this overlap from hospital to the community.

(GP of Deirdre, 56 year old female, GBM)

While the existing hospital-based specialist nurse coordinated care and liaised closely with community palliative care services, this involvement sometimes came to a natural end when active treatment was over²³, particularly for patients who were geographically distant from the tertiary centre.

10.4 Palliative care services

Close liaison with palliative care services played an important role in helping those working in primary care keep patients in the community setting. While some patients deteriorated quickly and died before primary care could take over their care, it was most often at this stage that local palliative care teams become involved,

If he then becomes into a more terminal stage of the illness, then, you know, that would be, we would then involve the Macmillan nurses locally and probably the palliative care service locally.
(GP of Henry, 65 year old male, GBM)

Provision of care varied in rural areas, where GPs were more heavily involved due to lack of specialists in palliative medicine,

Well we have a different approach locally here because of our rurality, we actually have more hands on, I think, carers for palliative cancer patients. We have, actually, the facility to admit patients to our local [hospital] as well, under GP care, which is fantastic. Because we can bring folks in and release, sort of, tensions and review the medications, treatments.

(GP of Robert, 36 year old male, GBM)

²³ Although this was not always the case. On occasion, if a close relationship was built up, the specialist nurse had continued contact with patients throughout their illness. There was no consistent formal management of patients at this stage.

District nurses also played an integral role in providing nursing care for glioma patients at the end of life,

And certainly when there became concerns about pressure areas, I asked the district nurses to become more involved.

(GP of Harriet, 64 year old female, GBM)

Specialists liaised with those working in primary care to keep people at home,

We always get good back up from secondary care if someone has a terminal illness and they need a little bit of additional help or whatever, if need be, we can get pretty good relationships with secondary care. Erm, nothing major, occasionally a bit more nursing care. Erm, you can get night sitters reasonably easy, erm, we are fortunate in having a night nursing service which not everybody everywhere has. So that makes life a bit easier for people to be kept in their own home wherever possible.

(GP of William, 64 year old male, GBM)

However, there were some barriers to the provision of palliative care. Lack of referrals to hospital palliative care services were reported as preventing appropriate physical and psychosocial palliative care for in-patients,

I believe we're not being referred. I think we could help out more. [...]Then I'm thinking, actually we've interfaced with a fair number of patients but almost, kind of, by accident.

(Consultant in palliative medicine 2, hospital-based)

In remote areas, there was difficulty in providing in-patient specialist palliative care as a result of distance from the inner city hospices,

This is a very emotive subject at the moment. We did have beds in [hospital ward]. But the [hospital] is having to make huge cuts, so [ward] has been closed. [...] As I said before, we have community hospitals, but they have all lost 11 beds as well, with all these closures, so we are really stretched with beds at the moment.

(Community palliative care nurse 4)

Reported experience of sourcing aids varied across different regions,

The biggest issues that people find are those perhaps that have a longer prognosis and who struggle to get adaptations to the house in the time that they want it.

(Consultant in palliative medicine 1, hospital-based)

Elsewhere, getting hold of appropriate aids at the right time was positively evaluated,

Even hoists and wheelchair service, which have been fantastic, I have to say. You know, from times that we have had to plead for wheelchairs really, really quickly. They have been terrific.

(Community physiotherapist 1)

10.4.1 Timely involvement of specialist palliative care

Timing of involvement of specialist palliative care was a central issue for the community palliative care teams in particular. There was an emphasis on early involvement,

And you felt if you have been involved earlier things would have gone a bit better for the family. Cos obviously, at this point, the patient was beyond caring, and it was the family that was left distraught and distressed.

(Community palliative care nurse 1)

One nurse specialist felt that they were able to raise the topic of a palliative care referral at diagnosis, but that it varied depending on how ill people were,

I would say about maybe, about half of people diagnosed with high-grade gliomas are more than happy to discuss support from palliative care, particularly if they're having very palliative treatment.

(Neuro-oncology specialist nurse 2)

Timely intervention was also an issue for district nurses and allied health professionals,

Because it is nice to have a bit of a relationship before they are coming to the very terminal stage of their illness.

(District nurse 3)

And having seen these patients sometime in the later stages, we have spoken about how much better it would be if they had some kind of communication with me, in the earlier stages. Cos you can imagine how distressing it is for a family who are perhaps, someone who is confronted with someone who has become very disabled very quickly. And then, we go in and say, well you need to bring the bed downstairs and you need a wheelchair. And they don't know you from Adam. You know, it's hard.

(Community physiotherapist 1)

There were other system barriers to providing timely and appropriate care,

We have to fight, one of these last ones, we had to really fight to get the equipment into houses. Not basic equipment like, beds and commodes and chairs and that. But big stuff like stair lifts and ramps, things that are expensive. Because of their diagnosis, social services are really reluctant to put, to spend a lot of money putting equipment in. Basically because it is not worth it. Which really irritates me.

(Community palliative care nurse 4)

There was concern that becoming involved too early in a patient's journey could interfere with people getting on with their lives and having too many people involved in their care. Getting the balance right was difficult, especially when dealing with two sets of different needs,

You know, that impact is, can be destructive, it can be a positive outcome, but for some people it can be quite destructive in building relationships if it comes too early for them. [...] And the needs of the patient might be quite different from the needs of their carers.

(Community palliative care nurse 3)

You can do a lot of damage, I think, if you go in too soon. If somebody is not ready to accept that their prognosis is what it is, and then we go in and start talking about the end stages, not that we would do that.

(Community palliative care nurse 4)

Moreover, early referral for in-patient specialist palliative care was not always welcomed,

And interestingly, recently, patients who have probably been inappropriately referred far too early from neuro-surgery. Who really haven't had their treatment plans sorted before they are

actually being referred for inpatient care in the hospice. And that has been, we have had a run of a few patients like that and it has created some tensions.

(Consultant in palliative medicine 3, hospice-based)

10.4.1.1 GPs' views on timely palliative care

On the whole, GPs supported the early involvement of community palliative care teams, helping to ensure continuity,

If they're introduced when, even sometimes when people aren't actively needing the treatment, so when perhaps they do become unwell and want to have more involvement, they know already who they might see.

(GP of David, 48 year old male, brain stem glioma)

Crucially, timely involvement of palliative care nurse specialist also meant the timely procurement of essential aids and equipment to enable caring for patients in the community,

They're great, the sisters are great at helping, knowing what kind of, sort of, equipment's available, you know, helping even with sort of, things like getting, sort of, the right bed or chairs that will help people, so they're sort of, really helping in ways that sometimes the district nurses would find it much harder to get certain people equipment that you can get through the hospice very, very quickly and easily.

(GP of David, 48 year old male, brain stem glioma)

GPs also emphasised patient resistance and the importance of a sensitive, responsive approach,

We got the palliative care nurse to visit. You know, quite near the beginning because we thought his prognosis was so bad. And I don't think he was really very keen on that. [...] And I think she was in too early. She knows that and he knows that.

(GP of Ron, 64 year old male, GBM)

10.4.2 Achieving appropriate care

The ability to provide the most appropriate care for people with a glioma was important to health professionals. Characteristics such as a relatively young age and complex symptom profile (including the cognitive and behavioural element) made it difficult to coordinate appropriate care. Meeting the needs of younger patients was particularly problematic,

And yes, older people do get brain tumours, but you do find they tend to be, well the two I have had recently are both in their 50's. Or even younger, much younger. And there's nowhere. They don't want to go and sit in a room full of geriatrics. The fact that we probably, we don't have a hospice but I think the community hospitals serve that purpose. But we have no day hospice facilities. Or no facilities for younger people.

(Community palliative care nurse 4)

There were also financial implications,

It is much harder to get funding for younger people. Because, if they go into a care home for example, there is only 3 care homes in [town] that take people under 65 and they are very, very expensive.

(Social worker 2)

Rehabilitation was another area thought to be lacking in terms of appropriate care for young persons with a diagnosis of glioma who had a good chance of a period of stability and a reasonable quality of life,

Well I guess, if we are talking particularly about the glioma patients, then it's often a younger age group and young men. And you know, perhaps after their initial diagnosis and treatment, they would like to be rehabbed back to where they were, or as near to. Most of them will be, you know, very fit and they want to get back to being fit and doing sport again. And what we found is that, that there is a real gap out there for these people. There isn't a lot of rehab available and certainly not, or hasn't been until recently, a lot of neuro rehab available for them.

(Community physiotherapist 1)

Provision for patients with altered cognitive states was also problematic,

One of the issues always was that the patient was actually kind of well from the waist down. And they needed sometimes, custodial care but they were kind of not appropriate for the hospice. And we were always sort of struggling as to where was the best place to care for that kind of a patient who had a longer life expectancy than maybe, probably for a hospice. But really family couldn't manage. Cos of the sort of behaviour problems.

(Consultant in palliative medicine 1, hospital-based)

Concerns about appropriate place of care for patients who are ill, but not in the terminal phase of their illness, were shared with other professionals.

Local care was perceived as appropriate, but not always possible,

To me she looked like a lady at almost end stage. And I thought, why is she going to the [hospital]? Why couldn't she come to our local hospital? Why did the man phone [nurse] when he had a GP half a mile down the road? And why are we excluding the GP and the nurses locally. Nobody knew how unwell this woman was.

(Community palliative care nurse 5)

Being able to provide around the clock support for carers was also raised as an issue by community palliative care nurses. Relatives caring for their loved one at home often struggled at night when it was not possible to provide full-time nursing care. There was a mixed response among community specialist palliative care nurses about whether this level of care should be expected and available to people. Lack of resources were reported to be the source of gaps in care.

10.4.3 Gold Standards Framework (GSF), Cancer and Palliative Care Registers

The advent of practice-based cancer and palliative care registers were also referred to, not always explicitly, by practitioners in primary care. The registers involved weekly multi-disciplinary meetings to discuss cancer patients, their progress and care needs in

addition to identifying when patients should be added to the palliative register. The initiative was supported,

And we also have regular palliative care meetings in the practice as a team, where all the partners, [...] the district nurses and the MacMillan nurse attend. And we go through all the patients who are, at the moment, receiving palliative care. Or a new diagnosis of cancer. So everybody's aware of the patients in the practice. And that's a new thing we've done and that's working well actually.

(GP of Ewan, 21 year old male, GBM)

A smaller number of professionals also mentioned the GSF specifically,

We have an excellent district nurse here who's, is very involved in palliative care. And everybody in the team is fully signed up to the Gold Standard, is that what it is called? Yes, the Gold Standards Framework.

(GP of Wilson, 58 year old male, GBM)

The GSF was reported as having a positive effect on the supportive and palliative care offered to people,

You know, it is a very good service here. And I think now, since they have introduced the Gold Standard Framework that the GPs are all working from. And they have all got the palliative register and looking to identifying people and letting us know. It has certainly improved.

(District nurse 1)

So that's where the Gold Standards come in. Where, you know, and everybody in that practice knows all the cancer patients particularly when they phone up. And then you look, right, is there a DNAR in the house? DS1500? Does the out of hours know about this person? And does everybody know that this person had 'X' or something like that and you know, cannot be cremated, you know? So it's all communication isn't it?

(Community palliative care nurse 6)

Others admitted that there was still a way to go to improve palliative care services in the community,

I think, just some general tightening up the way they are dealt with within a sort of team. And I think we, we do have quite a good service with palliative care, but probably make it tighter and

having more meetings about the individual patients. And I know that is what the Gold Standards for Palliative Care recommend. And I don't know that we do that particularly brilliantly.
(GP of Ian, 46 year old male, GBM)

10.5 Out of hours services

Out of hours services were not reported as a pertinent concern for GPs. However, other health professionals raised a number of issues, particularly district nurses and specialist palliative care nurses working in the community. Out of hours services appeared to vary around different regions. There were concerns about continuity of care through adequate provision out of hours: lack of 24 hour care and information and support for carers leading to inappropriate 999 calls and subsequent inappropriate case management,

I am seeing far more patients with an already diagnosed brain tumour coming back here. Rather than primarily going to the [hospital]. Especially out of hours, especially at weekends. [...] There isn't a management plan that says, in the event of this or this or this or this, this is the management plan. So we are taking patients with an already established diagnosis into an area where we should be talking about patients who are presenting out of the blue with a completely new condition.[...] if somebody has got a specialised condition and they have got used to the specialist and their team who is dealing with them, then why does acute medicine get involved again?

(General physician, acute admissions)

They go home to die and they have a fit, and the relative knows that they have had a fit and knows that they are probably going to be alright, we are just a bit worried. So just phones NHS24, just to see. And from that moment it is almost inevitable that the patient is going to end up in the [hospital], and they are going to be admitted to the [hospital] and it is going to be 3 days before anybody knows anything, but which time they will be on a morphine drip in the corner and they'll die in hospital.

(Consultant neurologist 2, district general hospital)

Moreover, lack of resources were available to allow people to be cared for and die at home by providing rapid response support for family carers, particularly out of hours,

The onus lies with the carers for 90% of the time. And you know, I think, when we are offering the patients choice of where they want to be cared for and where they want to die, I don't think we provide an adequate service at all.[..] I think there are huge limitations with what can be offered from district nurses, from community carers. Sort of popping in, being there for half an hour, an hour and then away and invariably something happens when they are away. There's not a response, there's nowhere for carers to get the help that they need as a rapid response. [...] You know, at the weekends or out of hours, overnight, there's huge gaps.

(Community palliative care nurse 3)

There appeared to be a variety of measures in place to try and avoid this happening, however, there was no universal management plan that had been made clear and available to all patients,

We could say that, all patients with gliomas should have a special note for NHS24, which we certainly don't do locally, but we do for our palliative care patients. I guess, if there was a note on the system saying, this patient has a glioma, immobile, catheterised, on anti-convulsants, has had fits in the past. If needed to be admitted, try the specialist palliative care team etc etc. That sort of thing is worth putting on, I think. That might make people's paths smoother.

(Consultant in palliative medicine 1, hospital-based)

Effective services were available in certain parts of the country but not consistently,

But he has my contact details, I have given him an out of hours form, because that's a key part of maintaining people at home. Is to have a specialist contact out of hours rather than phoning NHS24. So we are the exited from the NHS24 system for patients with palliative care needs.

(Community palliative nurse 5)

For some, out of hours district nursing services were available,

They give them the team district nurse number for, you know, the business day and then they give them the out of hours numbers as well.

(Neuro-oncology specialist nurse 1)

However, 24-hour care was not readily available (although this was the case to a limited extent in one region) to help keep very ill patients at home,

24 hour care at home is almost impossible. [...] And that can just be a little bit of an area, you know, if somebody really needs someone there all the time, and you can't provide them. It is not through lack of wanting to provide them.

(District nurse 3)

10.6 Communication and information

Communication and information issues were high on the agenda among professionals interviewed.

10.6.1 Communication with patients and relatives

The need for better information for patients and relatives was recognised. The early time before confirmed diagnosis was cited as a time when information was lacking,

We don't really give the patients an awful lot of information. It's very much, oh we will find out everything on Wednesday (clinic day). [...] They don't always like to kind of, tell the patients exactly what, you know, how serious things are. And sometimes, you know, there's a lot of, sort of, heads down and shuffling about on the ward round after biopsy.

(Nurse practitioner)

Better information leaflets were considered to be a welcome improvement to increase patients' knowledge of what was happening to them,

I don't think the information leaflets we have in our clinic for, give patients, are necessarily the best. Because they are very generalised. And there is not actually an awful lot of information on them. So sometimes I think if we had our own information leaflets, we can perhaps provide, slightly more detailed information and it is more appropriate for patients going through our department.

(Consultant oncologist 1)

But there is a definite desire for almost, for a map at the start. You know, I need to know what my GP is going to do, what my nurse specialist is going to do, what my consultant is going to do. Who do I phone if? How do I contact this person if? What on earth do I do about all this medication? And how do I manage the finance stuff? What do I tell my work? How do I speak

to my kids? So, the real breadth of stuff that can't be all dealt with within the first consultation, because the first consultation is about really important clinical issues. But there is a desire for some kind of, a map, people describe. Now whether that's a handbook, a leaflet, a signposting to resources, I'm not really sure.

(Maggie's centre staff 3)

10.6.2 Communication between health professionals

Breakdown in inter-professional communication dominated accounts of communication issues. On the whole, hospital-based professionals felt that communication was fairly good amongst those they worked closely with,

I think we have got quite a good system here. I think we have got good flow of information.

(Consultant neurosurgeon)

Yeah, I have no complaints about communication issues within this sort of, neck of the woods. Whether it is all in a bigger picture, sufficiently joined up, I don't know.

(Neuropsychologist)

Similarly, people working in the community were also generally satisfied with the communication amongst their own team,

And as I say, we do, we just work, we are lucky in [town], we work as quite a close team and we do have a good relationship with all that are round about. Which makes a difference.

(District nurse 3)

I think communication down here is excellent. We all attend multi-disciplinary, the practice meetings. I attend them in all the GP practices that I work with. Some are monthly, some are weekly. But the GPs, district nurses, ourselves are, we are constantly in touch. So yeah, there is no problem.

(Community palliative care nurse 4)

However, inefficiencies in information sharing when working as part of a multi-disciplinary team were recognised,

Medical staff have their documentation, nursing staff have documentation, we have separate documentation. The physios have separate documentation. So as an OT potentially, I would need to write into three sets of notes on a daily basis in order to communicate effectively with the team.

(Occupational therapist, hospital-based)

What we do find though, is it doesn't matter how much you write in the notes, people don't read it. [...] But equally I have heard people saying, well it's all jargon, or we don't understand what you mean.

(Physiotherapist 2, hospital-based)

Communication was perceived to fall down when liaising with people working in different settings,

I think, the difficulties arise in communication between departments in the hospital.

(Consultant oncologist 1)

10.6.3 Communication between secondary and community care

Problems with outreach communication were noted,

They tend to forget that, you know, hello, I'm out here in the middle of nowhere. Nobody has told me anything.

(Community palliative care nurse 1)

I think there's an endemic problem with the speed at which we communicate information from outpatient clinics.

(Consultant neurologist 2, district general hospital)

The problematic flow of information between settings was perceived to be exacerbated by a long distance from the treating hospital,

There are a lot of people involved and sometimes it can just be the communications that can get missed occasionally. And you can imagine when you have a centre likes of [town], [town], community, communication can sometimes be difficult among those 3 areas.

(District nurse 3)

Communication from tertiary centres is a problem. Not so much with glioma patients as others, I have to say. But, you know, letters from [town] take a very long time to come, so the GPs are taking these patients back into their care before they have had a discharge letter.

(Consultant in palliative medicine 1, hospital-based)

Those working in the community often reported delays or lack of communication about what was happening with particular cases, and sometimes they were not informed at all. In one area of Scotland, a summary was sent to GPs as soon as the patient had been seen in clinic to help ensure continuity, but this was not standard across regions,

They get it that afternoon after the diagnosis clinic. And it is just giving them enough information to go with at the beginning.

(Neuro-oncology nurse specialist 1)

Problems with communication appeared to work both ways, with hospital-based practitioners expressing similar views,

And I think there is also problems at times, between the hospital and the community. GPs are increasingly difficult to get hold of. We have been trying to get hold of a GP for 2 weeks, despite, every time I ring, he is in surgery, and I have left repeated messages.

(Consultant oncologist 1)

Communication between regional and local general hospitals was also a problem,

They are admitted here in the hospital, I am consulted chronologically in regards to them and expected to discuss anything relevant with them without having any kind of information. [...] I mean, it is obviously much more unpleasant for the patient and carers, when they meet a doctor who is not really in the full picture of what's going on.

(Consultant neurologist 1, district general hospital)

10.6.4 Improving communication and information

There was a shared idea that the route to improved service provision was through better communication and increased awareness through education,

By giving more education and running education sessions, then hopefully there will be a better understanding of what everyone's role is and support that is about out there, and we will be able to provide that.

(Charge nurse, oncology)

Better use of available technology to improve communication was suggested by a number of health professionals,

Probably a confidential email line between the [hospital] and here. [...] So, if we had that system with the [hospital] and [nurse] could email us and say, this person is known to me, you don't need to make contact yet. [...] I think it would be email in some system like that rather than phoning and taking time and bleeping. [...] If somebody invents a better system then I'll be the first to try it out.

(Community palliative care nurse 5)

An online system was also suggested elsewhere as a way of accessing a summary of key patient information and relevant appointments in order to treat and support them effectively if they were admitted or came to a clinic in a remote hospital.

10.6.5 GPs views on communication

GPs were also happy with communication for the most part and similarly reported working well together as part of a multi-disciplinary team,

We, we're a small organisation here in terms of medical organisations. We like to think, at least, that we can communicate pretty well across caring agencies, essential care, private, you know, professional carers and family carers. Erm, but it is an issue and we need to keep on our minds all the time.

(GP of Henry, 65 year old male, GBM)

Erm, the girls here [receptionists] are quite good in telephoning, you know, or talking to people. They are quite good. And especially if the patient's have been with us for a length of time, we know them quite well. I think that's the advantage of being in a small place where you know everybody and you know the patient, you know the children, you know the wives, you know the extended families. [...] So erm, small places are good for continuity of care.

(GP of Sandy, 47 year old male, GBM)

GPs were also more critical of communication across settings,

And timely communication is the key. So that you're not waiting weeks for a report to come in because somebody is saying well we haven't had the result of my scan, have you heard doctor? You know, you get that a lot. And, you know, that's a huge cause of anxiety for people.

(GP of Henry, 65 year old male, GBM)

Having a named individual to coordinate care was suggested to ensure efficient and effective communication across boundaries.

GPs called for improved communication between secondary and primary care about dosage and side effects of medication, particularly for steroid use,

There does seem to be some confusion between us, the hospital and [patient] in terms of the dose of Dexamethasone. [...] The other doctors have er, sent letters commenting on the fact that, you know, nobody seems to ever know what dose he's meant to be on or what dose, when it's last been changed and so on. So, you know, perhaps it might be a good idea if these patients carried a card around, they are going to be on Dexamethasone for a long time, and anybody who changes it, you know, could then make an entry, so everybody knows what's going on.

(GP of David, 48 year old male, brain stem glioma)

10.7 Holistic and existential/spiritual care

There was a great deal of variation in terms of how much professionals attended to holistic and existential/spiritual issues. Palliative care specialists and the hospital chaplains often considered holistic care to be lacking,

I think there's a lot of lip service paid to spiritual care. That we talk about this holistic care, body, mind and spirit, but it's still very much the, you know, still very much the emphasis is on the physical.

(Hospital chaplain 1)

Referrals were not always made to the pastoral care service, perceived to be caused by lack of awareness from ward staff,

Well I think one barrier is access and you have got to get to the patients and the relatives first. And that comes back to the whole business of referral. And we are really very dependent on staff understanding what our role is and being comfortable in referring.

(Hospital chaplain 2)

The chaplains interviewed wanted to become registered allied health professionals with access to notes and official referrals made. They often relied on good working relationships with particular wards or departments, meaning that patients didn't receive a consistent service across the hospital. There was a lack of awareness about what spiritual care meant, and chaplains were keen to stress that their remit was much broader than religion. Furthermore, there was no apparent commitment among health professionals or managers to incorporate spiritual care into patient care.

A hospital palliative care consultant commented on the impact of lack of communication between chaplains and other staff,

Even if pastoral care is involved in supporting patients, there is no way of knowing because they can't document it in the case notes. So that's like a huge handicap, that the pastoral care person might have gone in and had a really good discussion with the patient. So I think, sort of, the multi-disciplinary recording because people are documenting in different places it's, it's not very cohesive.

(Consultant in palliative medicine 2, hospital-based)

On the whole, holistic needs were being increasingly recognised, although there were perceived barriers to being able to openly address these needs within the medical team,

And hence you hear a lot from patients when they complain about something not to do with their medical care or medical, they always say, sorry I am wasting your time. I'm sorry you may not want to hear this, I had better talk that with my GP or the nurse. They feel like they are a bit reluctant, a bit shy to talk about it. But I think NHS, or current health service all around the world, is gone beyond just drugs and surgery and, it's more about, it's holistic care which is provided also for patients.

(Specialist registrar in neuro-oncology)

10.7.1 GPs' views on holistic patient care

In general, GPs felt they did have a role to play in providing holistic patient care.

Holistic care was generally conceived of as providing for *all* the dimensions of patients' needs and those of their family including physical, social, financial, psychological and spiritual needs. There was some debate about how far this 'total care' should or could go.

Occasionally, GPs did attempt to take on the total care of patients,

So sometimes I feel like I am a psychologist and a social worker as well.
(GP of Robert, 36 year old male, GBM)

However, there was a consensus that there had to be a limit to meeting patients' total needs and a line had to be drawn, or appropriate referral made,

The health service cannot be everything to everybody. And the other people, or agencies or families or whatever have to do their bit to an extent. And I guess what we need to be aware of is that that is actually happening and if it's not happening then take steps to make it happen. So our role is to make sure that it happens but it's not our role to provide it.
(GP of Henry, 65 year old male, GBM)

There was also a thread among interviews suggesting that it was not possible to meet *all* of people's needs. One GP became quite angry at the suggestion,

No, I don't think we can, I don't think we should even aspire to meet their total needs. We can aspire to meet their total medical needs. But their total needs may have all kinds of different aspects with their family, with resolution of family conflicts. With erm, meeting aspirations that they have of long held ambitions. Things that we have no control over whatsoever, so we can't possibly aspire to meet their total needs. [...] Do you think, well what do you think? Do you think the NHS should be aspiring to meet their total needs?
(GP of Andrew, 45 year old male, GBM)

10.8 Supportive care

Talk of supportive care was fluent amongst health professionals working with glioma patients and their relatives. On the whole, the service offered to people with a diagnosis of glioma and those alongside them was considered to be good,

Of the support to the person with the diagnosis and to their family, they are always, those that I have met, hugely appreciative, particularly of the nurse specialist service. They seem to feel that they are communicated well to in terms of the information support, but also in terms of their emotional support. They feel a confidence in that they are listened to and that they have access to a service when they feel they need it. And that, I'm really impressed with in terms of the service to brain tumour patients here in [town].

(Maggie's centre staff 4)

There were potential supportive services available to patients outside of the NHS to help them deal with a range of psychosocial issues,

There is this period of time when treatment finishes that people feel very lost and confused and unsupported. And that's where we come into our own.

(Maggie's centre staff 2)

Staff were aware of the need to pick up on the multi-dimensional issues facing the person with a glioma diagnosis,

But actually sometimes there are other issues come out of it which is almost not a cancer problem, but there is some wider issues than just, so you've got to be perceptive as a radiographer.

(Radiotherapist 2)

People with a diagnosis of glioma were considered to have distinctive needs that warranted increased support,

It is difficult for them to just go home and just accept it and absorb it. And majority of glioma patients don't have anything to do, so there is no self induced risk factors like smoking. They

are, just something happens, so when they are at home they are just sitting between the walls, thinking why me? Why is it happening? How am I going to pay for this family?

(Specialist registrar in neuro-oncology)

CPN: I think the big thing I find with brain tumour patients is, is the losses. In that they lose so much of themselves and are often have an inability to communicate or move or really do anything. They are so dependent on their carers.

I: And do you think that sets them apart in some ways, from other maybe cancer groups and also other illnesses, non-malignant?

CPN: Yes, I think it does. Because I would think the majority of them, due to medication or steroids and things, you know, their body changes completely.

(Community palliative care nurse 4)

A consultant neurologist described issues specific to people with a diagnosis of a low-grade glioma,

You have got a brain tumour, but don't worry, it might be 10 years before it kills you. And there is nothing we are going to do about it just now because, well, you know, we want to save that for when you are really in trouble. But by the way, you can't drive, you are on these tablets and you won't be able to get life insurance. You know, so all of that is very complicated and I think, in terms of, not so much in terms of the medical model of care of glioma, but in the, as you say, the social, emotional, psychological support, based at the time of diagnosis. These are generally younger people, they are people in work, they are people with young families, you know. You see someone who is 30, you have got a brain tumour and you are going to die sometime in the next 10 years, that's a hugely different psychological barrier.

(Consultant neurologist 2, district general hospital)

This neurologist described ways in which people's transition through the health services could be better supported with increased information and counseling support as part of a managed clinical network supported by a specialist nurse.

However, support needs were not always acknowledged,

You find that surgeons are very much, sort of, you know, I did this, he came in and I did this, they are fine. Fullstop. They are away. And it is sort of, forgotten, you know. It's very clinical. [...]I feel that, you know, as a unit we don't really do an awful lot to help the patients with their sort of, understanding and their kind of, coming to terms with their diagnosis.

(Nurse practitioner)

10.8.1 GPs' views on Social and emotional support

For some GPs, supportive care was central to the ethos of primary care,

It will be a very sad day when it comes to that the General Practice doesn't involve that [supportive care]. I mean, to me, it's a very important chunk of, not only in general practice and the GP, the whole primary care thing, it is absolutely what we should be providing a lot of the time.[...] I don't think I would be doing the job if it was just purely about dealing with medical symptoms and nothing else.

(GP of Mary, 76 year old female, AA3)

Part of this role was to help patients deal with what had happened and interpret what they had been told by the hospital. This was a sentiment shared among many GPs,

You can help people with, you know, guiding them through it as it were. Trying to be their interpreter and their advocate.

(GP of Henry, 65 year old male, GBM)

Being involved in this way meant that issues were flagged up and dealt with in a timely way rather than being acute problems that came to light too late. GPs also highlighted the facilitation of a relationship between patient and GP in anticipation of a need to be more heavily involved at a later date.

10.8.2 Barriers to providing supportive care

Many professionals did not feel that patients' support needs were being met,

But probably, from a support mechanism point of view, then no, we are not, because as we just said, we don't really have contact with any of the other health professionals. And I think there is a gap in the knowledge of, from my experience.

(Charge nurse, oncology)

Supportive care was where the service was thought to fall down, particularly during periods where patients were well and had no overt medical or specialist nursing care needs,

I think the potential area of gaps is possibly when they're quite well or perceived to not have a nursing need. That they may fall through the net.
(Health care manager 1, oncology services)

Lack of time was cited as a reason for not being able to meet patients' emotional needs, particularly in a hospital setting,

I think time wise, up in the wards because it's an acute hospital, nurses don't have time to spend time, I mean they do their best, you know and if somebody really needs to be sat down and have a chat... I don't know..emotionally, if we had more time.
(Physiotherapist 3, hospital setting)

We don't always have the time to sit down and sort of, explore how the patient is dealing with their diagnosis. [...]I think with brain tumour patients, there's often a lot of difficulty in terms of coming to terms with their diagnosis. And because we are often talking about short time intervals, we often don't have time to wait for, for ages for things like psychology. Perhaps with brain tumour patients there needs to be more sort of, access, more quick access (to psychological services).
(Consultant oncologist 1)

A common sentiment reported in interviews was that people's broader needs and expectations were so varied that it was impossible to meet them all,

Their needs are variable. And it's the unseen needs that you don't pick up on very often. [...] People have misconceptions about what we can actually achieve for them. When actually it's not in our remit or our ability to be able to sort out that problem.
(Radiographer 2)

Responsibility for dealing with supportive care issues was assumed to lie elsewhere and staff did not want to interfere,

If you are saying, are they imaged appropriately, are they operated on appropriately and are they managed post-operatively and their oncology treatment? Yes, I would say they get a very good standard of care. If their needs, if you are extending that to psychological support and holistic support, I don't know. [...] I don't see that as the role of the surgeon. I don't see that as, I would neither have the time nor the expertise to do that.

(Consultant neurosurgeon)

Perceptions of lack of skill were common,

I think I would be referring, I want to be referring more people to that service (psychology) than I am able to. And I feel I'm trying to compensate for that, but I am not a psychologist. I've got counselling skills to a point, but a lot of these patients need something more than that.

(Neuro-oncology specialist nurse 2)

Geography also interfered, with a support group unable to continue in a rural area,

We did have a [support group] down here. Which we started about 5 or 6 years ago. But it really never took off, probably because of the geography, I think, because the [county] is quite widespread.

(Community palliative care nurse 4)

A health care manager suggested that greater funding should be dedicated to developing psychosocial care and support for brain tumour patients as a whole,

One of my driving ambitions is to try and get the charities to do something a bit more creative because they seem to be a bit fixated on scientific research. And the small grants that they can offer will never make any major scientific breakthrough, but actually could do a whole power of work with psychosocial support, to the nursing support and so on.

(Health care manager 2, oncology services)

Some professionals felt that it was not realistic or possible to meet all of people's needs and expectations,

But I think a lot of that is to do with expectations. Cos often, you know, oh the MacMillan nurse will do this and the MacMillan nurse will do that. [...] MacMillan are guilty of that themselves though, because you know, they put these adverts in the papers and on the television. You know, we are all singing, all dancing answer to everything, and they are not. So, as I say,

people's expectations get built up. And then when they actually come to the reality of the situation, it's sort of, well we don't do that. We can't do, nobody can do this.

(Community palliative care nurse 1)

I think they (glioma patients) are quite a complicated group, I think, because of the uncertainty. And I don't know that anybody can meet, taking away that uncertainty. So for me, it is living with it. So it is not any lack of information or any lack of support. I don't know that anything could actually make the difference.

(Consultant neurologist 1)

10.8.3 Carer support

While supporting informal carers was often accepted as part of the role of professionals, it was not always provided,

That's probably another area where we lack, we don't really offer a great support mechanism for the patient's relatives or carers.

(Charge nurse, oncology)

I also think that again my opinion, we don't do enough family conferencing.[...] In terms of this is where we're going, this is what we're offering and this is what we expect and often it's kind of hit and miss.

(Consultant in palliative medicine 2, hospital-based)

Lack of resources was cited as inhibiting support for carers in a hospital setting,

We don't have the resources. [...] On a hospital ward we don't do that. We are kind of, very much focused on the patient. And the needs of the relatives, although you try to be supportive, we can't go that extra step in terms of setting up extra support outside of the hospital ward. Whereas the hospice are better at that.

(Consultant oncologist 1)

In a hospice setting, the issues distinctive to people with a brain tumour diagnosis were recognised as adding strain for informal carers,

I think we do recognise, certainly within the hospice that the needs of the carer are just as valid as the needs of the patient. And somebody who has got a glioma and in many ways more so because they are the ones who are struggling with the changes of what is happening, the inability

to communicate, the loss of mobility and sometimes the feeling of guilt that they are not able to look after the patient at home.

(Consultant in palliative medicine, hospice-based)

Support for young people with a family member with a glioma was also mentioned in several interviews as lacking.

Respite for carers was one area signaled for improvement,

More in the way of respite care. For people to have holidays, I think that's a huge issue. Because families, no matter how much services are in the community, will always take a huge load, a huge part of the burden of care.

(Neuro-oncology specialist nurse 2)

I suppose we try and support them by putting carers in, proper carers in, so that they can get a bit of relief that way. And we try and support them, so do the district nurses and the GPs, but there is not a formal way of doing it.

(Community palliative care nurse 4)

In addition, increasing carers' awareness and knowledge of end of life decisions such as resuscitation when people were dying at home was highlighted,

Oh, we're actually, we're trying to sort of, make sure that patient's relatives are aware of the do not attempt resuscitation policy, and not to phone 999 if somebody dies. So that the police and the paramedics come pounding in and it is all very distressing. So that is something else, that's another initiative that's kind of, adding into the sort of, quality of the journey I suppose. As much for the carers because they are the ones that will be left with all the mess.

(Community palliative care nurse 2)

Elsewhere, it was suggested that the carers themselves posed a barrier to support,

I, I think that informal carers often, with patients like this, often find it very difficult to not leave the caring themselves. It is quite difficult for them to let people in. I don't think we are very good at, I'm sure we are not providing respite care. But I am not sure that it isn't respite, in the house, that's truly needed.

(Consultant in palliative medicine 1, hospital-based)

Finally, juggling carers' information needs and wishes with those of the patient was also problematic,

But the wife wants to know more so that she can gain some control of the situation. And, but, and finds it very hard if you can't give her too much more information, if that's not what, unless you get the consent of the patient.

(Neuro-oncology specialist nurse 1)

10.8.4 GPs' views on carer support

The majority of GPs felt some level of responsibility to meet the support needs of carers as well as patients,

Trying to support his wife a bit. Erm, she obviously is quite distressed about the whole situation.

(GP of Henry, 65 year old male, GBM)

Some GPs felt they had a good service to offer carers,

The carers get an enormous amount of support. There's also a carers co-ordinator in this section of the city.

(GP of Winnie, 59 year old female, GBM)

It was also highlighted that supporting carers was an extension of patient support and affected their well-being,

But yes, I think it's very important to address their er, concerns because they're going to have an impact on him.

(GP of Ewan, 21 year old male, GBM)

Many GPs highlighted the difficulty of supporting carers of patients who were not registered at their practice. GPs stressed the importance of good communication with patients and counterpart GPs to ensure adequate support was in place.

10.9 Summary

Interviews with general practitioners and a range of other health, health-related and social care professionals provided a different perspective on services offered to people with a diagnosis of glioma and their families. The specialist neuro-oncology service was considered to be good overall, particularly the specialist nurse role, but suffered from lack of resources and delays related to communication. In primary care, some GPs saw their role as minimal while others were more involved in diagnosis; follow-up; monitoring; symptom control; emotional support for patients and their relatives; and overall co-ordination of care. GPs saw their role as changing over time dependent on the patients' needs and came to the fore after patients' initial treatment was over and they returned to the community setting for care and support. The shift from secondary to primary and community care was also recognised by other health professionals working closely with glioma patients and there was an emphasis on continuity and a community-based approach. Those working in palliative care services in particular were wary of timely involvement of their services. Some GPs and community palliative care practitioners mentioned the Gold Standards Framework as helpful in providing appropriate care for patients with a terminal diagnosis of glioma. Being able to provide effective care to patients out of hours was also reported as a significant problem with many inappropriate admissions and poor continuity of care.

Communication and information sharing issues were, like patient and relative interviews, high on the agenda of key problems. Breakdown of information within and particularly between settings was cited as the cause of the gap in continuous high quality services. There were mixed views about professionals' ability to provide for the holistic needs of patients and their informal carers. Those working in the community or according to the palliative ethos of care were more likely to aim to meet or coordinate total care needs. The need for better supportive care was recognised by the majority of

professionals interviewed. However, issues such as not believing supportive care was their role; not being adequately specialised or skilled; or having the time, resources or proximity to meet people's supportive care needs were reported, particularly in the hospital setting. Those working in the community appeared to have more of a focus on and commitment to supporting patients and their relatives. Carers' needs were also recognised but not always met by staff.

Chapter Eleven: Discussion

In this chapter, the practical application of the methods described in chapter three are reflected upon and challenges in data generation and analysis discussed. In addition, the findings presented in chapters five to ten are integrated and discussed in relation to existing research and theory and recommendations are formulated.

11.1 Reflections on methods: strengths and weaknesses

There were a number of advantages and disadvantages of using an in-depth qualitative multi-perspective and longitudinal approach.

11.1.1 Recruitment and retention

The process of recruitment worked well. Participants were provided with adequate information about the study and were approached by a trusted source and given the opportunity not to proceed without coercion. Being based at the site of recruitment helped to build relationships with the staff who helped to identify patients and passed on information to them. Attending weekly multi-disciplinary team meetings, daily trips to the ward and sharing office space with the neuro-oncology team also helped to make my face as the researcher known to staff in addition to giving me an insight into the hospital management and ongoing care of glioma patients. In practice, recruiting and retaining patients in the study was not as difficult as anticipated. People were very willing to participate, despite there being no obvious benefit to them personally. This was perhaps because patients were more willing to take part in a study endorsed by the hospital staff. Moreover, building a relationship facilitated retention of participants

towards the end of their life (Steinhauser et al., 2006a). It was important for me as the researcher to be personable, supportive and to remain focused on the ethical issues of working with patients and their relatives to maintain relationships and retain participants over the course of a number of interviews. I received positive feedback to this end.

11.1.1.1 Missing voices

People who were very ill, confused, or had memory loss were excluded from the study on ethical grounds. Very elderly patients who were not considered for any specific treatment were referred to local palliative care services and lost to the study. I was reliant on the staff acting as gatekeepers and so it was possible that some patients who may have been eligible were excluded from recruitment. Potentially, a significant proportion of patients could have been missed from study participation in the above ways, arguably those most in need, and their experiences may have been under-represented. However, use of a longitudinal approach offset this issue to an extent. In cases where patients were recruited at a time when they were lucid and able to consent, getting to know the patient and their relative meant that I was able to continue interviews as the patient declined. It remains, however, that those who were very ill from the very beginning of their illness with progressive decline did not have their voices heard. It is possible that some creative methods such as an observational study following these patients into specialist palliative care services could have captured their experiences. Or a more flexible approach of interviewing the carer only in these cases could have accessed their experience as a proxy. In fact, as participants in this study declined and in cases where they lost the ability to communicate, their relatives became increasingly dominant. Unfortunately there was no alternative and the difficulty remains with how best to capture the views of people at the end of their lives.

There were two cases where patients did not initially feel able to take part in the study around the time of their diagnosis. Using a flexible approach to recruitment enabled me, with permission, to re-visit these people and recruit them at times two or three. This method attempted to ensure that these participants' concerns were captured and their reasons for not initially wanting to take part were discussed.

There were two further cases where patients were approached but declined outright to take part in the study. At this time of crisis, they cited their distress and having too much else to think about as their reasons for refusing. In addition, there was one case where a participant felt unable to continue with participation in the study. This participant found it very difficult to think about what she was going through and went on to suffer with clinically significant distress and depression. In these cases, ethical integrity was the primary focus and the wishes of these patients were respected.

11.1.2 Multi-perspective interviewing

Interviewing patients, relatives and the professionals involved in their care gave a rich insight into glioma and the impact it had on people's lives. The potential of using multi-perspective interviews in this study and seven others was also recently published in a BMJ paper I co-authored to encourage wider use of this method (Kendall et al., 2009)(see Appendix 14).

11.1.2.1 Building comprehensive accounts

Speaking to patients and carers gave perspective on the shared experiences of the patient and those closest to them. There were complementary accounts, as well as differences in what was said. The health professional interviews provided an overview of the management of glioma patients and a different angle on key issues. Combining

these views gave a comprehensive account of the study topic. However, with it came a complex dataset and there were implications for the analysis of such a large volume of data (see section 11.1.4 on analysis) (Kendall et al., 2009).

11.1.2.1 Paired vs. separate interviews

A number of the interviews conducted in the present study were done as patient-carer pairs where both participants wished to be interviewed together rather than separately. The decision to give participants the choice about whether or not to take part in joint or separate interviews respected their autonomy. Given the difficult time in their lives that participants were approached, it was important to foster as safe and familiar an environment as possible for people to talk about their illness. It was a case of ethical integrity reigning above the research agenda. Some relatives acted as advocates or gatekeepers to protect the patient (Davies et al., 1998), but occasionally they facilitated recruitment, depending on the dynamics of relationships.

While this thesis aimed to consider the shared experience of patients and their relatives, there was a danger that individuals were not represented and their views conflated into one. Arguably the account given with one's partner present could be very different to one where the participant was on their own and had the opportunity to voice problems or concerns they would rather not tell their partner about. However, I found that in cases where people had particular concerns they did not want to share with their loved one, they were more likely to request a separate interview. It is possible, of course, that these concerns only came to light because of the privacy of a separate interview. However, there were cases where I suspect people chose paired interviews for fear that a separate interview might 'force' them to talk about issues they might not be able to face. Also, participants requested to carry on with either joint or separate interviews depending on what they had initially chosen, so it is possible that new issues arising

that participants did not want to discuss with one another could be missed. There was an instance where it became clear in an interview that information about prognosis was being withheld from a patient to protect them. In this case, an additional interview with the bereaved carer revealed this information, suggesting that a mixture of paired and separate interviews provide the best outcome. See Appendix 13 for an additional case study on multi-perspective interviewing to illustrate the ethical responsibility placed on researchers.

Although separate interviews appear to be considered the 'gold standard' approach to qualitative interviewing, there were benefits to the joint approach. Talking together in an interview elicited more information as participants prompted one another about topics or experiences they may not otherwise have remembered. Joint interviews provided a rich insight into shared experiences and had particular utility when patients had cognitive or communication deficits (Pratt, 2002). It also gave people a unique insight into how their loved one was feeling when they might not otherwise have known, something that was commented on in interviews. This in turn had implications for the interview process as an intervention in itself that changed the person's experience. This is an unavoidable side effect of any research in this field. Again, it was important to be aware of the potential impact this could have.

Joint interviewing of research participants was a valid method of inquiry where I ultimately needed to be responsive to the needs of participants (Morris, 2001). Use of joint or separate interviews also fitted with the aims of the study. However, caution was required in interpreting joint interviews accordingly when compared to separate interviews in the analytic phase (Gysels et al., 2008b). Coming from a social constructionist stance when interpreting data means that you are giving weight to the context in which the interview came about anyway. Understanding the number of people who contributed to an account simply added another layer to this interpretation.

11.1.3 Longitudinal approach

The use of a longitudinal approach had many benefits when conducting an in-depth qualitative research study. It was well suited to an exploratory study of subjective experience and identified change over time as well as enduring concepts. This method also helped to build a relationship with participants to enable a safe and trusting environment in which to discuss sensitive personal issues such as death, dying and existential concerns that may not have otherwise been raised. Some participants mentioned that I had become known to them and this made it easier to talk to me. Furthermore, a series of interviews, culminating in some cases with a bereavement interview, provided a sense of 'completeness' and closure for people. Longitudinal interviews provided a combination of prospective and retrospective accounts, allowing a complex but unique insight into personal experience. While people are often more able to reflect and articulate events with hindsight, accessing prospective accounts provided important information to understand experiences as they happened in 'real-time' in order to tailor services accordingly. Serial interviewing also gave the opportunity to monitor distress over time. Gysels *et al* concede that they were unable to gauge the distress of participants in their single interview study after the interviews had ended (Gysels et al., 2008a). A longitudinal design meant that contact was maintained and issues of distress were more closely monitored and addressed.

There were two main difficulties with the longitudinal approach in this study. The first was the large volumes of data collected for analysis (see section 11.1.4). Secondly, it was difficult in practice to capture the complete illness journey longitudinally, particularly the time when people began to deteriorate and reach the end of life. Patients had often completed their planned participation in the study by the time their disease progressed. For example, Ewan remained well throughout his participation in the study and coped well with aggressive treatment. As planned, interviews ended six months after the end

of initial treatment (concomitant chemoradiation). It was not until a year later that Ewan's glioma recurred and his health deteriorated and eventually led to his death. While a bereavement interview with Ewan's father gave some indication of events during this time, these experiences could not be captured prospectively and in first person. The study was designed based on the expected survival of patients with a diagnosis of glioblastoma multiforme and was also subject to the usual time constraints of a research study. The end of life period was difficult to capture on the whole because of the unpredictable nature of the disease. Other participants deteriorated very quickly or died suddenly and were lost to follow-up. The inclusion of low-grade glioma patients made an all-encompassing view of the trajectory difficult among this group. Distinct issues were identified among people with a low-grade glioma and health professionals indicated that it was a different trajectory reflected in their different management of these patients. Looking back, the illness trajectories of this group of patients were not adequately captured. A longer study exploring the more chronic illness experience of low-grade patients would therefore be appropriate.

A more fluid and flexible study design that triggered interviews based on key transitions in their illness journey could be considered to capture subjective experience. However, there are ethical reservations about this approach. In practice, it would be difficult to discuss with participants when they were well and could preclude their right to be fully informed about the research agenda and process. Research focusing solely on the terminal phase for glioma patients would supplement this broader view of experience over the course of the illness, perhaps identifying patients through palliative care services or at the hospital from the point of recurrence and following them from there.

The precise definition of the QLL method remains unclear (Holland et al., 2006). Re-telling someone's story is presented by Saldana as having a beginning, a middle and an

end (Saldana, 2003), but I think you are only gaining an insight into a very particular part of someone's life and a presentation of it that they are choosing to give. You *are* looking at a snapshot, albeit a more complex one that allows you to look at processes, transitions and endurances in that time, which are valuable in themselves. I have co-authored a "Research Methods and Reporting" paper on the potential of the QLL approach in health service research in a recent BMJ paper (Murray et al., 2009)(see Appendix 14), but there remains scope for enhancing the understanding of the method and its usefulness (Riley and Ross, 2005, Murray et al., 2009).

11.1.3.1 Reflexivity and private vs. public accounts

Using a longitudinal approach gave better access to more personal or private accounts over a more public narrative. From a reflexive stance, I had to consider my role as a young woman and also someone potentially perceived as affiliated with the health care system. I was explicit in telling people about my background in psychology and stressed that I was not a doctor. These factors could have impacted on people's perceptions of what they should or shouldn't tell me as well as representing what I brought to the interaction with participants. In turn, the narratives elicited were shaped by the historical, temporal and social context in which they were constructed. People may have wanted to convey a particular image of who they were and how they were coping (more detail on how this relates to coping is discussed in section 11.2.2). I discovered in one particular case that one family carer, Angie, had been withholding certain information about how difficult she was finding her relationship with her husband Wilson, because she did not want to worry or upset me unduly. In another case, William appeared to be endorsing a more Parsonian role as the sick person passive to the interventions of a paternalistic model of medicine and had nothing but praise for the health care system and all of those within it; with only small signs of the

struggle underneath this. Finally, Sandy, in the weeks before he died, said to me that I should not be doing this job at my age and seeing 'death'. These examples give an insight into how I was viewed by those I was interviewing and reflexive practice, including discussions with colleagues, helped me to see this. Being able to build a relationship with participants over time enabled me to gain access to a different account, perhaps closer to a more intimate knowledge of their experiences (Murray et al., 2009). It is unclear if accounts changed over time in certain cases, such as that of Angie not discussing with me the difficulties she had been having, as a result of her changed perception of me (or me of her) as we got to know one another²⁴, or for some other reason. It was difficult for me to detach myself from this kind of situation to assess what factors influenced the accounts constructed and so reflexive practice was important. Inter-disciplinary discussions with colleagues; multiple perspectives from interviewing a broad range of participants (including multi-disciplinary professionals); and attending multi-disciplinary meetings and patient and relative support groups helped to facilitate reflexive practice.

11.1.4 Conducting research with 'vulnerable' people

Considering the needs of participants was paramount. It was important to monitor distress and fatigue and act accordingly if there was cause for concern. I tried to look out for non-verbal cues; gave participants time in interviews; paused if necessary and was very careful about the topics introduced. I used the NCCN Distress Thermometer to look for clinically significant distress and discussed cases where there was cause for concern with the research team. I monitored physical decline and worked closely with relatives and health professionals when patients could no longer communicate

²⁴ And of course replaced with different but still powerful new assumptions that continued to shape our interview accounts.

effectively. In cases where informed consent could not be established, interviews were no longer conducted with patients but continued with carers where possible.

Participants were also reminded that they could withdraw from participation at any time if they felt unduly distressed or tired without giving a reason. The factors outlined here all contributed to fostering a 'safe context' for participants (Pratt, 2002). Sensitivity, consideration for participant welfare, joint interviews with loved ones present and conducting interviews on familiar territory also went some way to creating a feeling of security and safety for people taking part.

However, I found that participants were willing to take part in interviews and expressed beneficial effects for themselves. Participants described a number of advantages including making sense of their experience; talking it through from start to finish; understanding how their loved one felt; talking it through being cathartic or therapeutic; contributing to research; and helping other people affected by glioma in the future. There were cases where participants were neutral about taking part and a small number of people explained that it was distressing to talk about certain issues but it was something they had to face. The positive aspects of taking part in such research studies reported here confirm findings elsewhere in the literature exploring the effects of participation in interviews for very ill people (Davies et al., 1998, Harris et al., 2008, Gysels et al., 2008a, Gysels et al., 2008b).

11.1.5 Interviews with staff

Conducting interviews with health professionals presented a very different power dynamic (Pope and Mays, 2009), and in itself emphasised the role that both parties brought to the interaction, changing the account created. Reflexive practice here helped to address these issues in the interpretation of the data. Another issue related to the

challenges of telephone interviewing. Non-verbal cues can be missed, and time pressures meant that many issues were possibly not explored in the same depth as face-to-face interviews. However, practical constraints on GPs' time and availability meant that this method had to be used.

Special care had to be taken to preserve the identity of staff members interviewed, as some worked in quite specialised roles. The diversity of staff interviewed in such specific roles made it difficult to amalgamate their views. This approach did, however, provide a rich understanding of how services worked and the management of glioma in a variety of settings.

The timing of the GP interviews on the illness trajectory meant that I was unable to fully capture their involvement over time, particularly toward the end of patients' lives when GPs anticipated heavier involvement. I attempted to time GP interviews as late as possible in patients' trajectories but practicalities meant that this was not always possible. It would have perhaps been more valuable to nominate one health professional most involved in patients' care, rather than GPs who had variable involvement, and then follow the identified individual over time. However, it is possible professionals may not have been able to commit to several interviews.

11.1.6 Analysis

The process of analysis was complex and time consuming in order to make best use of the data. A number of issues were encountered.

11.1.6.1 Managing large volumes of data

Multi-perspective qualitative longitudinal interviewing produced vast quantities of material for analysis, something 'likened to an analytic albatross' (Holland et al, 2006; Murray et al., 2009). In a study exploring subjective experience and, in particular, changes over time, such volume of data can inhibit the depth of analysis required to do the data justice. Therefore, it was important to prioritise directions of analysis in order to avoid being overwhelmed and focus on key themes.

11.1.6.2 Use of the constant comparative method

Using the constant comparative method on such a large number of interview transcripts was time consuming and complex as this had to be done across all interviews at one particular time and across all interviews over time. Emergent themes were not only developed across a single time, but were further refined and evolved as serial interviews were considered. Initially, I planned to report on the key issues identified at each time or stage of the illness journey. However, it soon became clear that organising the analysis according to key issues (identified during the coding process described in chapter three) and then examining how these developed over time avoided repetition of particular topics that were evident at each time point. Furthermore, there was no predictable or coherent timescale to encompass all patients' trajectories. Patients had different concerns at different times, with the exception of reaching a formal diagnosis, which were more easily combined under topic headings.

11.1.6.3 Alternative approaches

A case study approach with a smaller set of interviews may have lent itself better to an exploration of subjective experience. Narrative analysis could have been used to analyse each person's story. Having a smaller dataset would have allowed a greater depth of analysis and examination of change over time. However, this had to be balanced with a diverse range of experiences and theoretical saturation of views to ensure the topic area was fully covered to adequately inform service recommendations. There are ongoing studies in the University of Edinburgh Primary Palliative Care Research group examining the best use of the qualitative longitudinal method in exploring progressive illnesses that will shed light on how best to proceed²⁵.

11.1.7 Translation into practice

There are some important considerations about the translation of narrative form into evidence-based medicine and practice. Rich, subjective information needs to be operationalised into public policy in order to bring about change and ultimately improve patient care. At some point, the main messages from these rich narratives need to be reported as a summary to ease dissemination. One must therefore infer general rules from an in-depth study of subjective experience. In evidence-based medicine a general rule is necessary in order to plan interventions and change practice. The richness of a qualitative study allows theory to develop which can in turn inform future

²⁵ Conducted by Anna Lloyd and Emma Carduff exploring the best use of the qualitative longitudinal approach and management and analysis of the data in relation to the frail elderly and colorectal cancer patients respectively.

practice. An insight into subjective experience is also invaluable to be able to shape responsive behaviour from health professionals based on a patient-centred ethos of care. Although qualitative research is not *statistically* generalisable nor does it seek to be, it is theoretically transferable and has currency in understanding the issues for people in similar situations and can therefore add a rich concept-driven contribution to the evidence-base (Barbour, 2000). There are potential cultural differences between qualitative researchers and policy makers that need to be addressed in order to translate, transfer and exchange knowledge, and a common language agreed upon to move forward with the translation of ideas into practice. While qualitative research is concerned with the micro level of understanding, it also provides a macro understanding (at a general theoretical level) that policy makers seek in order to bring about change for a wider population (Barbour, 2000). This qualitative research helped to develop theoretical understandings of the rich human experience of personal lives that should be at the heart of public policy. Statistics and trends are a vital part of understanding systems at a public health level but we also need to promote an insight into human lives and stories that are full of meaning (Corden and Millar, 2007).

Part of the transition from this exploratory study into actual changes in practice will necessarily involve further research and interventions evaluated using randomised controlled trials.

11.1.7.1 Generalisability

This study was based on a small group of patients being treated at a single cancer centre. However, the methods used provided a rich insight into the *subjective* illness experience of people on the glioma illness trajectory. Combined with existing research and theory, this kind of rich qualitative data can make an important contribution to academic knowledge (Barbour, 2000). Theoretical saturation of interview data also

implied that no new issues would emerge, suggesting that the main themes were covered.

There is scope for further complementary studies surveying a larger group of patients and carers informed by the findings from this study; perhaps nationwide via the Scottish Adult Neuro-oncology Network (SANON) in order to assess the frequency of some of the key findings.

11.2 Reflections on findings, existing research and theory

11.2.1 Reaching a formal diagnosis

Capturing the period leading up to a confirmed diagnosis of malignant cerebral glioma provided a rare insight into people's 'real-time' experiences of awaiting a cancer diagnosis. Unusually, participants in this study were already aware that something very serious was wrong with them. A mass or tumour had been picked up on a CT or MRI scan and so patients had already been given the possible diagnosis of a brain tumour. Eleven out of 13 cases interviewed at time one had undergone biopsy at the time of interview, but were unsure about their histology. The implications of a benign brain tumour are far more sinister than those of, for example, a benign breast tumour. And so patients in this situation were already suffering from shock and distress, but had the added threat hanging over them of a more immediately life threatening tumour. Therefore, the stories of people in this situation provided unique and dramatic data.

A powerful need was apparent among participants at this stage to relate their diagnosis story, setting the scene for the interview and providing a history and context to their lives as a whole. The need to talk through and tell one's story is evident elsewhere in

the qualitative research literature (Leavitt et al., 1996, Salander, 2002). This phenomenon implies an added value for participants in taking part in this kind of research and also a link with an active approach to coping with one's illness through the medium of talk (this theory will be developed further in relation to discussion on coping and information and communication) (Funk and Stajuhar, 2009).

The pathway to diagnosis was reported as very stressful for participants, reflecting the findings of a retrospective interview study with low-grade glioma patients (Edvardsson et al., 2006). Narratives around delays in diagnosis were particularly distressing and frustrating for patients, mirroring those reported elsewhere in coming to a diagnosis of cancer in general, influencing later interactions and satisfaction with services (Leydon et al., 2003, Grbich et al., 2000). Participants in the present study went to some lengths to try and understand why delays occurred and rationalise any difficulties encountered, again a finding present in the existing literature (Leydon et al., 2003). However, experiences of long delays did not dominate participants' experiences in the same way this issue does in the general cancer literature. This is perhaps due to the way in which some brain tumours present, with aggressive tumours rapidly becoming very obvious, and has been identified in relation to head and neck cancers elsewhere (Pollock et al., 2008). There were two types of presentation, which varied across patients. For some people, there was a gradual onset of symptoms that were not overly concerning and could be explained by a 'reasonable alternative diagnosis'. On the other hand, many presented with more 'alien' symptoms with greater cause for alarm, such as seizures, black outs or sudden changes in motor function, which often led to an emergency admission, findings evident in similar studies with glioma patients (Salander et al., 1999, Edvardsson et al., 2006). While the distinction between sudden and gradual presentation was not marked between subsequent high and low-grade diagnoses in the present study, this division has been previously described (Salander et al., 1999, Edvardsson et al., 2006). This difference may not be so obvious among the

participants in the present study because of small numbers of low-grade glioma patients, but incidences of both sudden and gradual onset were evident among those who went on to receive a diagnosis of high-grade glioma - although 'gradual' in this study was a period of weeks or months rather than months or years, and so the definition of gradual and rapid have some bearing on how these findings are interpreted. These findings are largely consistent with the existing literature in this area, suggesting that retrospective evidence, collected close to the period of study, makes a valuable contribution. However, real-time insights into the emotional reaction during this phase provided an additional contribution to understanding people's experiences.

Uncertainty is often at the root of the emotional reaction to a diagnosis of glioma and is a common instance associated with any cancer diagnosis, including brain tumours (Janda et al., 2006). It appears that uncertainty looms even larger during the period awaiting a confirmed diagnosis but shifts focus as new knowledge is accumulated. The disorientation caused by the shocking news of a tumour being detected and subsequent glioma diagnosis led to a great deal of uncertainty. Brennan describes uncertainty and the associated worry as a reaction to the 'amputation of the future' and all of the expectations it entailed (Brennan, 2001). A person's life is thrown into disorder, going against the nature of human cognition to plan and anticipate future events, having expectations about the future that are met consistently in order to function. The lack of order, characterising the intense uncertainty, results in a great deal of distress (Salander, 2000).

The real shock and distress experienced by participants in the period leading up to and immediately following confirmed diagnosis were highly prominent among this group of participants, and are common reactions to any cancer diagnosis. Findings from interviews during the pre-diagnosis period show that this reaction was present from

the moment people were told they had a likely brain tumour. This news created the response of flattened affect or 'emotional numbness' that impaired participants from being able to articulate precisely what they were feeling at this time. Interestingly, some work by Frank identifies a number of types of narrative as people attempt to tell the story of their illness (Frank, 1995). Frank's 'Wounded Storyteller' suggests that people use the medium of telling one's story (or narrative) to help them actively make sense of their experiences. The 'chaos' narrative describes a lack of coherent story as people are unable to make sense of what is happening to them. As a result there is no identifiable story at this time. This concept was useful when trying to understand people's emotional reaction at the start of their illness. While people were able to describe in great detail the period leading up to their brain tumour first being detected, they were unable to articulate their emotions at this time.

There was evidence at this stage in a person's illness trajectory of overwhelming shock, fear and distress before a histological diagnosis was confirmed, resonating with another study exploring prospective accounts of a range of brain tumour diagnoses (Wyness et al., 2002). Recognition of this important, often formative, period in a person's trajectory is needed along with a heightened awareness of troubling issues around the pathway to diagnosis that people may wish to resolve, in order to respond with appropriate support and then facilitate a better onward journey.

11.2.2 Coping and adjustment

11.2.2.1 Emotional reaction

'Real-time' interviewing may, in theory, not best capture people's experiences during the pre-diagnosis phase as they are masked by the shock. However, this in itself is a valuable insight that only became evident upon comparative analysis with subsequent

time periods, suggesting this period should be explored as part of a longitudinal study. Greater awareness of shock and distress at this time and the resulting emotional paralysis can better support patients and their relatives at this formative time in their illness. Understanding the processes of adjustment and the potential causes of poor adjustment can mitigate their impact (Brennan, 2001). The dynamic emotional reaction and individuals' varying ability to communicate their distress also adds further weight to longitudinal follow-up in order to capture the full picture of changing illness experience.

The diagnosis of a chronic illness has been described as a 'biographical disruption', an invasion of life as a person knew it, which is also relevant when understanding emotional reaction (Bury, 1982). However, this was not a static event, a change from one set of circumstances to another, but an ongoing process of change characterised by fluctuation and uncertainty. Bury describes it as a profound disruption that requires a "fundamental re-thinking of a person's biography and self-concept" [P169] (Bury, 1982). From psychology, cognitive theory is also relevant to understanding people's emotional reactions and sits alongside the sociological theory. If we consider that individuals have a set of core assumptions or expectations about themselves and the world around them, these constitute their 'assumptive world' (Parkes, 1971). These assumptions are shaped by experiences and are constantly refined as people have novel encounters and interactions with their world and expectations are adjusted accordingly. However, a traumatic event can shatter a person's assumptions, flooding them with new information so that they are temporarily disorientated as they attempt to make sense of it (Janoff-Bulman, 1992). In response, reactions of fear, shock, distress, anxiety, anger and worry were all evident among the participants in this study, and commonly in the literature (Wideheim et al., 2002, Wyness et al., 2002, Keir et al., 2008a). Distress is also argued to be greater and more enduring in brain tumour patients (Keir et al., 2008b). Brennan presents a social-cognitive transition model of adjustment that

encompasses this reaction to distressing news and emphasises the significance of a person's surrounding social and historical context (Brennan, 2001). Further examples describing the disruption to normal life and the necessary adjustment to a new set of circumstances have been described in relation to any diagnosis of cancer, and more specifically in relation to brain tumour patients (Little et al., 1998, Khalili, 2007). This model of adjustment will be revisited throughout the remainder of this chapter in relation to subsequent themes.

11.2.2.2 Coping strategies

As people began to overcome the initial shock of their diagnosis, they attempted to rebuild their lives and tried to make sense of what happened, accommodating it within their existing beliefs and adjusting their beliefs accordingly. Coming to terms with a diagnosis of cancer is essentially a processes of adaptation, a re-building of an 'assumptive world' to accommodate new information and experiences (Parkes, 1971, Brennan, 2001). The participants interviewed in the period leading up to a diagnosis had to do a lot of work in their accounts of their experience to try to deal with what was happening to them and work out how to cope as a kind of 'knee jerk' reaction to the news of their potential diagnosis. In doing so, a number of techniques were evidently used as part of the process of positive adaptation to diagnosis, including staying positive; fighting spirit; distraction, denial and disavowal; living in the moment; comparison with others; and using past experiences. The processes of adaptation seemed to vary considerably from person to person in the approach they used and their ability to successfully negotiate the turmoil they were experiencing. The repertoire of strategies employed here is highly congruent with Salander's work on cognitive manoeuvres (Salander et al., 1996, Salander and Windahl, 1999). The strategies used serve the purpose of protecting people from the painful reality of their diagnosis and

prognosis and created a sense of hope to enable them to cope. Hope, as a product of adaptive coping, will be discussed in section 11.2.2.3.

Living in the moment

The approach of 'taking it as it comes' or 'living in the moment' was reported by the majority of participants in this study. This provided a way of focussing the mind away from an unpredictable future and the associated distress this caused, working as a distraction technique. Living in the moment alludes to the Buddhist philosophy of 'mindfulness', explicitly mentioned by two sets of participants. This philosophy involves keeping a focus on the here and now, paying attention without qualification or judgment, and grounding oneself and one's thoughts in the moment. Practices of meditation related to mindfulness have been shown to reduce stress and anxiety and depression in the general population, cancer patients and people with other forms of ill health as well as health professionals (Grossman et al., 2004, McKenzie et al., 2007).

There appeared to be a tension between the natural process of time and moving forward and the resistance to thinking ahead to an uncertain future and what it might hold. Time passed and participants continued to go through transitions, experience treatments and other significant events, all the while learning new information. Yet they were working hard to keep their mindset rooted in the present. Participants described the difficulty of doing this as their mind ran away with them as well as having the urge to tackle the more practical elements of getting their affairs in order and planning certain aspects of their lives such as treatment, trips and holidays. This can in part be explained by a cognitive division between emotionally and practically living in the moment so that people can plan ahead but keep their emotions in check as well as a disavowal of the painful reality.

Distraction, denial and disavowal

Distraction appeared to be a common cognitive manoeuvre used in a number of different ways. 'Keeping busy' was frequently cited as an approach to dealing with one's circumstances, providing a means of distraction by having to cognitively attend to other tasks. This has been found elsewhere in brain tumour patients and their relatives who have busied themselves with practical tasks as a way of occupying one's mind (Wideheim et al., 2002).

A more obvious avoidance of distressing thoughts was also evident in certain participants. Rather than a complete denial of what was happening, as has been suggested in the past (Amato, 1991), this appeared to be a more conscious act of shifting the focus away from particular thoughts. While participants did show awareness on one level of their diagnosis and what this meant, they could actively avoid thinking and talking about it to protect themselves. Salander's discussion of the concept of disavowal is thus very relevant (Salander and Windahl, 1999). Disavowal was a form of conscious self-deception which served as an adaptive coping strategy to help people deal with the reality of their situation and function on a day to day basis. Rather than a stable cognitive state, this was more likely to be a pendulum between considering the reality and disavowing it, similar to the pendulum of hope and despair described in relation to dealing with cancer at the end of life (Sand et al., 2009). Moreover, disavowal was a defense, part of normal process of adjustment to a distressing and traumatic life event to block information that was too painful to contemplate or incompatible with existing assumptions about the world and one's place in it as people attempted to assimilate this information (Brennan, 2001, Janoff-Bulman, 1992). There was a strong link here with the role of information, people's ability to absorb it and the kind of information they sought. These issues are discussed further in section 11.2.3.7.

Staying positive and fighting spirit

Another dominant theme identified in relation to coping with a diagnosis of glioma was staying positive and having a fighting spirit. Again, these concepts are very familiar in the wider literature (Watson et al., 1991, O'Baugh et al., 2003). In contrast, there is also some discussion in the literature about the external pressure to 'be positive' and the potential damaging affect, a pressure expressed by some participants in the present study (Byrne et al., 2002). Byrne *et al* argue that patients may feel they have no choice but to display a fighting spirit as this is what is promoted by the health service and responded to most favourably and so patients suppress the distress they could perhaps benefit from discussing with health professionals. There is some question then about whether professionals are somehow colluding with patients and avoiding discussion of the 'elephant in the room', which could be extended to friends and family and even researchers who help people maintain their façade through their interaction with them and subscription to the 'positive mental attitude' narrative. However, as discussed in relation to the concept of disavowal, such defense mechanisms can be adaptive. There is a subtle threshold that health professionals need to be aware of in order to engage appropriately with patients and their relatives and help them in the most productive way.

Historically, there has been detailed exploration of the public persona portrayed by individuals and endorsed by those they interact with, particularly in relation to illness. Patricia Cornwell refers to a 'public account' in her study of 1980s Londoners with poor socio-economic status (Cornwell, 1984). People worked hard to portray themselves as hard-working, morally upstanding people who did not succumb to ill health. This position on health and illness relates to Goffman's 'Presentation of the Self in Everyday Life' which talks about the performance and the back stage view of a person who adheres to social norms of how they expect others want them to behave (Goffman,

1969). In terms of living with cancer, the socially endorsed attitude is one of the stoical patient, seen to 'fight' their illness to the bitter end and show no vulnerability. Evidence for this theory was present in some of the coping mechanisms used by patients and their relatives in this study. Goffman and Cornwell talk about the public performance as a kind of 'face-saving' approach to social interaction. However, I would suggest that there is more to it than this. Talking as a person who is positive and is coping successfully with their illness was perhaps a way of actively coping, where a person came to embody the role of the 'successful copier' and cognitively adapt to the role. Fighting spirit can promote a sense of internal control and, like disavowal, facilitate psychological adjustment (Brennan, 2001). Through language, individuals can 'talk' themselves better. This concept is discussed by Funk *et al* in relation to conducting qualitative interviews with family caregivers of people with cancer. The use of interviews as a medium for discussing thoughts and feelings is thought to be crucial to actively coping with their loved one's illness (Funk and Stajuhar, 2009). This can be extended to patients also and links back to the social cognitive transition model of adjustment (Brennan, 2001). Longitudinal interviews facilitated more private accounts as people benefited from a safe context in which to expose some of their vulnerability and darker thoughts on the other side of the pendulum.

Comparison with others

Discussing the situations of other people was a significant part of the narratives constructed in the study interviews. People often appraised themselves favourably in comparison with others. Downward comparison, the process of comparing oneself with those in a worse off position, was a helpful coping mechanism to re-evaluate one's own situation in a more positive light. Social comparison is a common phenomenon in social psychology (Festinger, 1954) and has been applied to the context of health and illness e.g. (Taylor, 1983).

Influence of past experience

Participants also felt that their past experiences were important in influencing how they managed living with a glioma. Brennan's social cognitive transition model of adjustment is useful in understanding the role of past experiences (Brennan, 2001). People's assumptive beliefs are formed by their early experiences and refined by new knowledge and experiences. Challenges to people's core beliefs can lead them to alter these assumptions, thus learning from experience. I would argue that the experiences we gain also help to shape our concepts of self and the world around us. If our expectations have been previously challenged, they can become more flexible to incorporate possible future events and, combined with other factors such as social support, influence subsequent adjustment (Brennan, 2001).

11.2.2.3 Hope

Hope became an overarching theme that threaded through coping. The importance of hope was clear in helping people to cope. Many strategies used to deal with a diagnosis of glioma, such as seeking reassurance, disavowal and positive thinking, all appeared to create and maintain hope. Like adjustment, people went through transitions of hope as they progressed through their illness, a hope that shapes and shifts as new experiences and information were encountered. The presence of hope is well recognised in the literature (Wideheim et al., 2002, Janda et al., 2006) in addition to its central role in helping people cope with their diagnosis or that of their loved one (Salander et al., 1996, Scheier and Carver, 2001, Clayton et al., 2005b). The issue of unrealistic hope has also been addressed in the literature and is tightly bound with the role of communication and information provision, presenting a difficult challenge to health professionals to foster hope, and therefore coping, without encouraging

unrealistic expectations promoting an enduring maladaptive response to one's circumstances (Hagerty et al., 2005, Clayton et al., 2008).

An important finding in this longitudinal study showed the nature of hope to change over time and vary considerably from person to person. In some cases, participants initially hoped for a full recovery but over time, and with the knowledge of a poor prognosis, came to wish for a period of good quality of life and in some cases, a dignified death. This finding suggested that hope is integral to 'getting by' when living and dying with a brain tumour, as has been found in other groups of brain tumour patients (Edvardsson and Ahlstrom, 2005). Those participants that remained well focussed on their physical health as a source of hope, a finding common in the existing literature where hope has been identified (Salander et al., 1996, Sand et al., 2009). Better physical health and functionality has also been associated with better quality of life and more successful coping (Gustafsson et al., 2006). The changing nature of hope has also been identified elsewhere (Khalili, 2007, Clayton et al., 2008). Kübler-Ross also talks about hope and how it changes for those with a terminal illness, the idea that 'if in barbed wire, things can bloom' [P123] (Kubler-Ross, 1989). People searched for hope despite the adversity they were facing, using hope as another method for coping.

Hope has multiple dimensions and definitions (Lohne, 2008, Elliott and Olver, 2002). While health professionals may be cautious about the ethical implications of collusion, an understanding of hope may enable them to support people in a positive way in their use of hope. A distinction made between hope as a desire in contrast with hope as expectation (collectively known as 'particularised hope'), can help us to understand whether or not hope is realistic and helpful (Wiles et al., 2008). Participants may desire a particular outcome but understand that it is not likely to happen. Hope as desire, linked with disavowal, can help people to stay positive and cope successfully with their illness whereas hope as an expectation could be damaging if it is not realistic.

Particularised hope contrasts with generalised hope. Generalised hope has no specific focus but gives meaning to life and protects people against despair, a kind of magical thinking which allows people to stay positive in dire circumstances (Salander, 2000, Wiles et al., 2008, Sand et al., 2009).

Understanding the role of hope as part of wider coping is central to responsive supportive care for people living with glioma. Hope appeared to be the product of a number of strategies to cope successfully with such devastating circumstances. As Salander argues, recognition of the use of 'cognitive manoeuvres' and their significant role in people's ability to deal with their diagnosis is vital, allowing the professional to 'work with' patients to get through their ordeal. Working against their chosen defense could in fact be very damaging (Salander et al., 1996). Helping patients by communicating realistic information in an optimistic way can help cultivate a positive supportive relationship and sustain hope (Leydon, 2008).

11.2.2.4 Social and emotional support

Social and emotional support have been identified as central to helping people adjust to living with a glioma. Some maintain that brain tumour patients have significantly greater unmet supportive care needs compared with other cancers (Janda et al., 2008), where others debate the level of significant unmet need in cancer patients more generally e.g. (Soothill et al., 2001a) versus (Piggot et al., 2009). The level of psychosocial need and extent to which these are met is thought to vary considerably among brain tumour patients (Lepola et al., 2001). Another study looking at quality of life has suggested that brain tumour patients have a relatively good quality of life (Pelletier et al., 2002). Much of this debate seems to be related to the varying measures used to assess need; different definitions of need; the time point in the illness that needs were measured; and what constitutes a significant need. However, much of the

research done, including the present study, highlights that while physical and medical needs are met, the psychosocial dimensions of support are lacking. I would argue that this understanding of people's experiences and what they consider to be important in supporting them through their illness adds a valuable component to other studies measuring whether or not people are satisfied with the level of support. In the present study, there was not an overall requirement voiced for increased support, but the importance of support from friends, family, professionals and, in some cases, peers, were stressed by those interviewed. Drawing on family in particular was named as a resource in helping people cope with their circumstances. A supportive environment helped to foster a safe context in which to make sense of what was happening as part of the process of adaptation in addition to being the vehicle through which people attempted to rebuild their lives (Brennan, 2001). There was variation in the preference for contact with other people going through a similar cancer journey. The findings here mirrored the literature on use of support groups in cancer, where individual differences were noted e.g. (Grande et al., 2006). Again, I would suggest that this depends in part on the approach to coping that people have developed and whether they view 'exposure' to other cancer patients as a safe context congruent with their beliefs as described at the beginning of this section on coping. Some people benefited from comparing themselves favourably with those around them whereas others were not able to face the similarities between themselves and others, and therefore process just how ill they were.

It became clear in the present study the extent to which participants valued supportive professionals, while lack of support and reassurance was the focus of negative experience. The value of professional support, particularly the specialist nurse, has been identified in the existing literature and innovative ways of making this kind of support available have been explored (Sardell et al., 2000, Curren, 2001). Showing an interest in non-physical issues need not be difficult or time consuming with the right

communication skills, yet can be perceived by patients and relatives as supportive. In the light of the discussion on coping and the need for a positive focus, I would suggest that the supportive professional role also provides a means of facilitating the processes of adjustment through provision of information coupled with encouragement and reassurance.

The role of positive communication and appropriate and responsive information provision were pivotal to feeling supported and facilitating positive adjustment. Moreover, the identification of the shift from secondary to primary and community care described in chapter ten emphasises the need to explore the continuity of support for patients and their relatives as their illness progresses, particularly for those who live for a long time. Therefore, there *is* scope for increased professional support for those living with glioma in meeting these needs in a particular kind of way and with the added purpose of supporting adaptation to one's diagnosis and constantly changing illness experience over time.

11.2.2.5 Carers' concerns

There were a number of issues specific to relatives or carers identified in this study. Carers required specific kinds of information in order to feel skilled in providing for their loved ones' needs. Carers described the strain brought about by their caring role in cases where their loved one became more ill and the caring demands increased as they struggled to balance these with other aspects of their lives such as work and looking after other dependants. Concern for patients and how best to care for them was also a common finding. Findings in the present study were reflected in the wider research on caring for a person with cancer as well as specifically for brain tumour patients (Wideheim et al., 2002, Sherwood et al., 2004a, Janda et al., 2008, Schubart et al., 2008).

A distinctive issue that emerged over time as particularly distressing when caring for a person with a glioma was the cognitive deficit and the difficulty of challenging changes in personality and behaviour. This profound problem has been previously reported as detrimental to carers' physical and mental health (Wideheim et al., 2002, Sherwood et al., 2004a, Janda et al., 2008). In fact, increased depressive symptoms were evident among carers whose loved ones had altered cognitive states (Sherwood et al., 2006). Although this dimension of caring for a brain tumour patient has been recognised and reported on both in the present study and the wider literature and policy, it was evident that carers did not feel adequately informed about what to expect and the nature of these changes or supported as they tried to live with them.

Carers also had to undergo their own process of adjustment to the devastating news of their loved one's diagnosis and to a different view of their own future. To this end, carers also need understanding and support to help foster adaptive coping.

11.2.3 Information and communication

Information and communication were found to be central issues for patients with a suspected or confirmed glioma, a finding that is recognised as immensely important in a large body of literature in this area e.g. (Fallowfield et al., 1995).

11.2.3.1 Lack of information

Lack of information, particularly in the early period around diagnosis and in the pre-confirmed diagnosis phase was signalled as the source of significant distress for participants. Lack of information at this time has been highlighted as a problem in previous research e.g. (Grbich et al., 2000), but this study adds to the evidence that this

lack of information started as soon as people made contact with health services and began investigations (Wideheim et al., 2002, Leydon et al., 2003). The early phase of the illness experience was crucial in shaping people's illness experience and negative words stayed with people, stressing the importance of positive supportive relationships being forged early on between professionals and patients and their relatives (Friedrichsen et al., 2000, Wyness et al., 2002, Mager and Andrykowski, 2002, Parker et al., 2001).

11.2.3.2 Tension between knowing and not knowing

Both patients and carers expressed a preference for very clear, direct and honest information about what was happening to them right from the beginning, which has been suggested in existing studies e.g.(Parker et al., 2001). Knowing was generally considered better than not knowing, in line with the majority of information literature (Fallowfield et al., 1995, Fallowfield et al., 2002, Wyness et al., 2002), although it has been suggested elsewhere that increased awareness was associated with increased distress (Davies et al., 1996b). Importantly, the desire for clear and direct information here was at odds with awareness among participants that they may not want to know too much detailed information, creating a tension or dilemma for people. It was clear that patients and carers alike wanted to know procedural information, telling them of the process of what was happening to them and what they could expect. However, it was less clear the level of personalised and detailed information about the illness and what the future might hold that people wanted to hear. There was a higher level of individual difference around this topic also. There was a strong desire among many to know this information so that people could know what to expect and plan ahead. Carers in particular wanted to know how best to look after their loved ones and felt under-informed. Again, a tension was evident around this as well as individual variation, with some patients and carers making it very clear that they did not wish to

think of the future or have any information about prognosis. This tension has been recognised to a certain extent in the literature e.g. (Rose, 1999) and there is certainly a degree of variation in the literature about the specifics of information people do and do not want, that could be explained in part by the tension theory (Wong et al., 2002, Jones et al., 2006, Pollock et al., 2008). There are implications here for providing individually tailored information to patients' and their relatives' (often separate) needs in a *supportive* context that makes processing difficult information easier.

11.2.3.3 Preference for positive and reassuring information and communication

Participants in this study appeared to control the levels of information they sought, and I would suggest this was in order to minimise their distress and promote hope. People preferred hearing information that was positive and reassuring, as previously described (Wyness et al., 2002, Wideheim et al., 2002). I would suggest that people sought this kind of information as it did not alter their expectations to the same extent as hearing more painful information (Janoff-Bulman, 1992, Brennan, 2001).

11.2.3.4 Ability to absorb information

Evidence identified for lowered ability to absorb information was also linked to coping. Participants were unable to take in a lot of information at the time they were told their shocking diagnosis. It is likely that a temporary 'shut down' occurred as people processed and tried to make sense of what was happening. This phenomenon is also linked to disavowal as part of the process of adjustment to cancer (Salander and Windahl, 1999). A person has an inherent need to defend the mind from information too painful to cogitate. Avoidance of this information impedes emotional processing and blocks the information from the person's mind as they attempt to make sense of it

and integrate a stressful and traumatic life event into their existing cognitive world (Brennan, 2001). There are important implications for understanding the complexity of information needs and their link to coping. Employing techniques such as provision of information followed by repeating and clarifying the information and providing regular opportunities for support allows people to digest information and process thoughts and feelings (Khalili, 2007). Strategies such as a patient-centred consultation style; giving patients time to talk uninterrupted; picking up on verbal and non-verbal cues; active listening; choosing appropriate questions with a psychological or social focus and in context; and using emotional words can also help to detect and address distress (Ryan et al., 2005). Provision of sensitive, tailored information to individual patients' and carers' needs at particular times can help minimise uncertainty. Furthermore, there is an important balance between making sure patients and their families are fully informed and fostering adaptive coping that allows for hope (Clayton et al., 2005b, Wiles et al., 2008).

11.2.3.5 Individual differences in information preferences

On the whole, the literature suggests that carers actively seek more detailed information than the patient themselves (Durity et al., 2000, Salander and Spetz, 2002) although it has been suggested that patients do want to know about their future on the whole (Butow et al., 1997). Interestingly, this distinction was not so marked in the present study although carers did seek specific information to help them feel skilled in looking after their loved one and in understanding changes, as seen elsewhere (Grbich et al., 2000, Clayton et al., 2005a, Schubart et al., 2008). In fact, gender differences were noted in both patients and carers, with males more likely to actively seek information compared with females in this small study. Also outlined in the literature was the distinction between 'monitors' and 'blunters' where monitors were more likely to seek information while 'blunters' avoided it (Butow et al., 1997, Parker et al., 2001), further

exemplifying the complexity of preferences. In the present study, individual differences in approach to information preferences were noted and the link between information and communication and the approach to coping was paramount. Understanding variance in approach to information and its link with coping strategies provides an invaluable insight into developing more responsive information provision. Information needs were embedded in people's experiences and perceived needs did not always reflect the information given, but rather were related to adjustment, level of anxiety and ability to cope (Pollock et al., 2008). Furthermore, information giving embodies a therapeutic relationship and provides patient-centred care, with implications for patient well-being (Wallace, 2001).

There was a temporal component to shifting information preferences such that how people felt at a later date was not necessarily how they felt at the time of the diagnosis (Grbich et al., 2000), emphasising the need for timely and repeated provision of information and also stressing the importance of longitudinal research to understand preferences. More detailed exploration of information needs suggests that they are complex and vary considerably for individuals over time and at transitions across the illness trajectory (Butow et al., 1997, Voogt et al., 2005, Maguire, 1999). For example, Butow *et al* found patients' preferences for being informed decreased after they had a consultation with their doctor and their preference for reassurance and emotional support increased at this time. I feel this emphasises the link between information and coping. As the authors argue, information and involvement preferences may shift when people come 'under threat' (Butow et al., 1997), but there are ways of making patients feel involved and thus supported that enhance patient experience (Fallowfield, 2001, Fallowfield et al., 2002).

In the context of Brennan's model of adjustment, people have become more vulnerable at a time when they have been flooded with new information and needed time and

support to process it (Brennan, 2001). The handling of information and communication around the time of crises or transitions in distress over the course of the illness (such as diagnosis, treatment, following treatment, progression/recurrence and the end of life) is therefore key (Kendall et al., 2006, Murray et al., 2007).

11.2.3.6 Becoming experts

As time went on, people accumulated more knowledge and adjusted their 'assumptive worlds' accordingly so that any new information was more likely to fit with their new set of expectations, what Pollock *et al* call 'experiential knowledge' (Pollock et al., 2008). People also became more flexible over time as a result of their experiences so that new information and experiences linked to their illness experiences fitted more easily with their thoughts and beliefs (Brennan, 2001). Accumulative knowledge had the effect of giving people back a level of involvement and control which some people chose to act on.

11.2.3.7 Information, communication and coping

The effect of giving information went far beyond the giving and receiving of knowledge to include the building of a supportive relationship between the two parties and the facilitation of successful coping for the patient and their relatives. People most valued honesty and clarity combined with empathy and support (Salander, 2002). The best methods for information delivery to people with brain tumours have yet to be fully evaluated (Davies and Higginson, 2003), but it is clear that positive reassuring communication that is sensitive to individual differences is needed to help people promote and sustain hope in order to deal with their devastating circumstances.

11.2.4 Managing and controlling illness

Again, there was considerable variation from person to person in life after diagnosis. Distinctive symptomology and differences in rate of progression of illness accounted for individual differences. The presence of a period of stable disease made a significant difference in how both patients and carers coped and progressed.

11.2.4.1 Impact on life

The lives of both patients and carers were forced to change significantly as a result of the diagnosis of glioma. Personal and social lives were disrupted as people were no longer able to continue doing the things they had done previously, leading to changes in relationships and, for some, to a marginalization and isolation over time, as is evident among cancer patients more generally (Courstens et al., 1996, Little et al., 1998). In many cases patients and their loved ones had to give up work, which had a knock on effect on finances and all other aspects of life. Patients with significant caring needs found it difficult to manage the loss of independence and accept another person caring for them. Not being able to drive was also the source of a great deal of frustration.

Bury's theory of biographical disruption described in section 11.2.2 on coping is useful in understanding the complete disruption to all aspects of people's lives and the distress this caused (Bury, 1982). A person's expected path was suddenly diverted and they began a transition into a 'liminal' phase, which took their life down a very different route (Little et al., 1998). Little *et al* describe 'liminality' as the process of transition people with a chronic illness undergo, using the specific example of colorectal cancer. With this comes a certain 'boundedness', external constraints placed upon the individual associated with a lack of power or control. These constraints work on a number of levels such as the practical constraints of not being able to get out to

loss of personal control as a person becomes subject to the medical system. This in turn may lead people to consider their self-concept and how this has changed.

While Bury has focused on the early phase of a person's illness trajectory, Little *et al* suggest the liminal state is both acute and sustained for the rest of a person's life so that they are not ever 'reincorporated back into the fabric of society' [P1490] (Bury, 1982). In the case of glioma patients, with a shorter life expectancy than many other progressive illnesses, this is more than likely to be the case. I found that carers also went through a similar transition and their journey should also be recognised. Suggestions that those with a chronic illness shift from a normal to an abnormal trajectory are questionable, however. It leads us to question what the norm or reality is and whether this breaks down under Little *et al*'s analysis, so that it no longer becomes meaningful. Sustained liminality *becomes* a person's life and reality. Perhaps Little *et al*'s theory is just a way of understanding the 'meaning journey' that people undergo as a result of any life changing event? In which case it could be extended beyond chronic illness to understand how any person's sense of self is shaped. However, this theory can give practical insight for health professionals into the multiple dimensions of the life changing experience of chronic illness.

11.2.4.2 Dealing with physical and cognitive problems

A diverse range of physical and cognitive problems caused distress and difficulty for people with a glioma. The extent to which people were affected also varied considerably. Patients were determined to overcome their difficulties and used strategies such as healthy eating, exercise and techniques to improve memory to attempt to regain their previous health. The difficulty of dealing with a range of physical problems has been recognised among brain tumour patients undergoing

palliative care (Fox and Lantz, 1998, Faithfull et al., 2005), and fatigue was perhaps the biggest common factor (Lovely, 1996, Lovely et al., 1999, Brown et al., 2006).

Experience of treatment was generally not problematic and participants were happy overall with the medical aspects of their care. This resonates with past research looking at experience of radiotherapy (Davies et al., 1996b). However, treatment options have changed as more patients undergo adjuvant and concomitant chemotherapy. Evidence from the present study has not shown any iatrogenic problems although it is not possible to discern whether increased nausea and fatigue have been associated with chemotherapy. Further qualitative research exploring people's experiences of modern day treatment regimes could add to our understanding.

The extent to which cognitive and physical problems were pervasive of everyday life had an enormous impact on people's adjustment and well-being. This finding is evident extensively in the literature where a period of stable disease was associated with less distress and better quality of life (Davies et al., 1996b, Giovagnoli, 1999, Davies and Clarke, 2005, Janda et al., 2007). There is also evidence for increased strain on carers and in their relationships with the patient when there was no period of stable disease, a finding confirmed by the present study (Salander and Spetz, 2002). Salander's concepts of 'time of disease' and 'time of everyday life' are helpful to understand the individual balance for people living with a glioma (Salander et al., 2000). Salander argues that more ill patients did not necessarily have poorer well-being and that 'time of everyday life' was still possible for those with poor functional ability. There is scope, then, for increased support to maximise people's time of everyday life regardless of functional ability. Furthermore, there is a suggestion that the nature of adjustment to circumstances and quality of life is more complex than simply cognitive and physical health. Personality and approach to coping also play an important role, as has been previously discussed.

11.2.4.3 Fear of recurrence

Participants were also living with the fear of their tumour progressing and more importantly, they were concerned with what this would mean physically in terms of how they would deteriorate and how it would impact on the lives of everyone around them. Moreover, glioma patients differed from many other cancer groups in that recurrence is a certainty, the uncertainty lies in when it will return (of course awareness of this was variable). Patients became distressed when they began to experience new symptoms. Interestingly, research has shown that brain tumour patients don't often attribute symptoms to treatment side effects (Taphoorn et al., 1994). As new treatments may be extending the lives of glioma patients, longer term treatment side effects may be arising, which could be confused with signs of disease progression.

Fear of recurrence is another phenomena widely recognised in the research literature as intrusive on the lives of people living with cancer (Lepola et al., 2001, Sanson-Fisher et al., 2000, Taillibert et al., 2004) and so the importance of recognising and supporting this concern in practice is paramount. In relation to the present group of participants, it was interesting to note that there did not appear to be any defining moment described in interviews when people were told that the tumour had recurred. In practice, there was more of a natural progression of the illness and deterioration in health and so people knew that things were not getting better. As previously mentioned, having had time to process one's diagnosis and adjust one's expectations may have affected people's reaction to progression of disease.

11.2.4.4 Aspiring to normality

An overwhelming theme that emerged after diagnosis and particularly after initial treatment was the attempt to rebuild one's life and try and get back to how life was

before the illness struck, a finding evident in existing studies (Little et al., 1998, Lepola et al., 2001). Being 'normal' was seen as important to enable people to function and regain some of the order they previously had in their lives and thus minimise anxiety and regain some independence and self-control (Salander, 2000). Regaining some semblance of normality is a sign of positive adjustment as people incorporate their new knowledge and experiences into their existing 'assumptive worlds' (Brennan, 2001). Engaging in previous everyday activities provided a supportive environment in which to process and make sense of what was happening while resuming such activities also provided the experience through which new assumptive worlds could be built and some shattered assumptions rebuilt. I would suggest that these tasks also provided a focus and a source of distraction for some.

There was evidence in the present study that people made a series of adjustments, practical and cognitive, to accommodate the changes that had occurred, arriving at a 'new normal' consistent with an altered assumptive world within the constraints placed upon them (Taylor, 1983, Little et al., 1998). This is also consistent with Bury's sociological theory where following the traumatic disruption to meaningful life, people mobilise their resources - psychological, social and practical - to help rebuild their lives (Bury, 1982).

Frank's categorisation of illness narratives is also illuminative. Following a diagnosis of any life-limiting condition, Frank suggests that people embody the 'restitution narrative' to actively restore life as they knew it (Frank, 1995). In doing so, people subscribe as members of the 'remission society', a cancer community who are still somehow separate from mainstream society in the same way. Little *et al* suggest people will never fully leave their label as 'cancer patient' behind them (Little et al., 1998). There was evidence in the present study that participants were adopting this narrative and its implications in order to obtain the order and functionality that go with it,

helping them to cope with their illness. Although there was varying awareness of prognosis, I find it interesting and noteworthy that people with a very poor prognosis set about to achieve the restitution of normality. One participant in this study called this 'the honeymoon period' suggesting an awareness that remission will come to an end. However, the apparent need for this approach again returns to the concept of hope and positive adjustment. Hopelessness would bring with it disorder and meaninglessness and, by extension, anxiety and distress.

The concept of restitution is also congruent with the notion of 'survivorship' that has been shown increasing attention in research and policy, having originated in the USA (Corner and Richardson, 2007, Department of Health, 2008). The term is now used for all cancer patients who have completed initial treatment regardless of prognosis, with a mixed reception among practitioners. The position of low-grade glioma patients is different and less clear. Further research into survivorship as it applies to different groups of glioma patients would shed more light on its application.

Understanding the role of restoring 'normal life' and its links with coping and hope underlines the significance of recognising and supporting the realistic goals set by patients and their carers. There are implications for rehabilitation in the neuro-oncology setting to give patients the opportunity to set particular goals to maximise their potential and improve well-being.

11.2.4.5 Practical and financial concerns

Practical and financial concerns did not take a centre stage in terms of people's priorities in interviews. However, participant suggestions for improvements to services often returned to practical issues such as parking and improving privacy and the hospital buildings, which have been shown to impact on people's quality of life

(Rowlands and Noble, 2008). Finances appeared to be of variable concern dependent on people's age and backgrounds, but issues around learning about what benefits may be available and filling out forms to obtain funds were common, as found elsewhere (Janda et al., 2006, Leydon et al., 2003). While people in the existing study and others prioritised the need for increased information and emotional support over practical needs, the latter were consistently reported as part of living with a brain tumour.

11.2.5 Death, dying and existential issues

Issues around death and dying were dealt with in different ways by participants, related to their approach to information seeking and individual differences in coping style. Some participants actively talked about death and sought information on issues around death from diagnosis, whereas for others there was a shift over the course of time and experience. For others again, acceptance of death came right at the end of life, captured in bereavement interviews.

11.2.5.1 Facing death

In the face of uncertainty, many questions about death and dying were voiced by a significant proportion of participants. Many were concerned with the physical side of the end of life and patients and carers alike wanted to know what to expect. Some patients in particular were concerned about pain at the end of life. *'How long have I got?'* was a common question and appeared to be bound up with distress and uncertainty about the future as well as fear of recurrence. In other cases, people were less willing to explicitly discuss their fears of death. As Adelbratt and Strang suggest, death anxieties were often pervasive, dominating fears and embedded in other fears when fear of death could not be articulated (Adelbratt and Strang, 2000). In certain circumstances people were willing to have discussions about very sensitive topics from first interview. There

was some recognition of this in professional interviews also but a hesitation by both parties involved. I feel this is influenced, in the case of patients and relatives, by the tension between wanting to know and not wanting to know and, in the case of health professionals, by a distinct lack of confidence in their ability to have such discussions, an enduring finding (Strang et al., 2001).

The discussion on coping and adjustment to living with a brain tumour is also relevant to understanding people's adjustment to dying and end of life issues. As people neared death, their approach to coping changed and they became more accepting of death. Familiar coping strategies did endure, such as distraction, positivity and hope right to the end of life (Strang and Strang, 2001). There was evidence in particular cases of loss of hope (Adelbratt and Strang, 2000). This seemed to happen in cases where deterioration was very fast and people did not have time to process and adjust to what was happening.

The need to get one's affairs in order appeared to be instinctive at the time of diagnosis. Again, I feel this relates to Brennan's discussion of adaptation to traumatic events (Brennan, 2001). It is human nature to wish to plan and predict one's future and restore order and control where it is lost. Furthermore, this shifts the focus away from the emotional pain of diagnosis and is therefore a distraction technique.

There was further diversity in terms of who was willing to talk openly about preferred place of care at the end of life. Not all patients or carers gave a clear indication of where they would like to be cared for but on the whole people voiced a preference for staying at home. Carers were particularly keen to do so while patients were concerned about the burden this would impose on their informal carer as their health deteriorated, a common finding e.g. (Khalili, 2007). It is important to be sensitive to whether this is something people would like to talk about – and discrepancies between patients and

carers – and tailor discussions accordingly. In many cases, discussions need not wait until they are close to death. Others were more closed to the topic and likewise, their wishes should be respected in line with the concept of ‘working with’ people’s approaches to dealing with their illness. Elsewhere, research has found carers to be more receptive to having discussions about end of life care, along with health professionals, while patients did not mention it (Clayton et al., 2005a). This supports the findings in the present study to an extent, as carers certainly had important information needs around caring for their loved one at the end of life, but patients were also willing to have these discussions in some cases.

Due to evidence that carers wished for more information and help to develop skills in order to care for people at home, increased support for carers is necessary (Faithfull et al., 2005), although the best and most acceptable methods of delivery of information to improve skills remains questionable (Wong et al., 2002). Clayton and colleagues presented the argument that patients could benefit from such discussions despite their fears. A number of factors affect whether or not people are able to stay at home (Gomes and Higginson, 2006). Evidence that keeping patients at home was still problematic - leading to acute admissions - suggests that there is still work to be done in planning end of life care more closely with those involved (Faithfull et al., 2005).

People were talking about death and dying from an early point in their illness, as echoed in another study of brain tumour experience (Wideheim et al., 2002). Thoughts and fears about death appeared to be present before a confirmed diagnosis was given. Therefore, there is scope in some situations for discussions on these issues between health professionals and patients at this stage. Having these conversations early on in the right context may help to dispel fears borne from uncertainty, achieve better palliation of symptoms and allow patients and professionals to work together on existential issues of ‘life closure’ (Khalili, 2007). However, one also needs to keep in

mind the extent to which people rely on health professionals for reassurance and hope, reading into everything that is said to them. There is a possibility then, that talking about some of the 'what ifs' may be taken on board as certainties, such that professionals need to communicate sensitively and effectively, with implications for communications training.

11.2.5.2 Community, primary and specialist palliative care

Patient reported GP involvement varied considerably, related in part to the individual working style of the GP as well as the level of medical input required. District nursing involvement was directly related to the level of input required. There is some concern in the cancer literature about timely and appropriate care, in particular the level of community nursing involvement in the early phase of a person's illness (Howell et al., 2008). There is certainly a need to understand the role of primary and community care in generalist and specialist palliative care (Murray et al., 2008) and to avoid overlap and plan continuous care across the transition from secondary care. There is considerable scope for improving information, communication (e.g. about end of life issues and planning) and support to promote hope and well-being among patients and their families. There is a need for a more multi-disciplinary approach to palliative care with greater involvement for non-specialists (Taillibert et al., 2004, McNamara, 2008, Murray et al., 2006, Shipman et al., 2008a). While this approach has been recommended in the NICE guidance for improving care for brain tumour patients, it has yet to become standard practice (NICE, 2006b).

Involvement of palliative care specialists varied, with those with poorer health more likely to have involvement from specialist palliative care services. There was no consistency in terms of timing or provision of care for becoming involved. There were some areas of dissatisfaction such as uncertainty about the process of what was

happening and when patients were expecting to see community specialist palliative care nurses again, but on the whole people were positive about their interaction with these services. A few people accessed palliative day care services, which have been shown to be satisfactory (Davies and Higginson, 2005).

11.2.5.3 Spiritual and existential issues

For a small number of patients, spirituality automatically meant religious faith to them. Those who practised a religious faith found enormous comfort as well as social support from their local church community. The majority of patients and carers in this study did not perceive that they had any spiritual or existential distress related to their experience of glioma. However, as present in the wider literature, some patients and carers did ask some existential questions and re-evaluate themselves and the meaning they ascribed to their lives (Edvardsson and Ahlstrom, 2005, Strang and Strang, 2001). There is some debate over the usefulness of thinking in terms of spirituality when thinking about coping with cancer (Salander, 2006). 'Existential' may be a more useful concept in considering the transitions people undergo in response to a traumatic event and can be understood integrally in the broader context of coping rather than a parallel or alternative explanation. Analysis and discussion of methods of coping in the present study has suggested that the process of adjustment to a diagnosis of glioma is more than just a biographical shift or transition, but also an existential one. So, while patients and their relatives may not have immediately viewed the thoughts and processes they had as existential, they could be considered as such.

For example, there was an existential element to cognitive adjustment to a shocking life event such as diagnosis of a glioma. There were ongoing transitions in each individual's sense of themselves and their world. An extraordinary event requires major changes in a person's 'life space' and requires a process of adaptation or assimilation (Janoff-

Bulman, 1992). Previously 'preconscious' assumptions about a person's existence were suddenly brought back into the conscious mind and people were forced to consider big questions around mortality and the common question of 'why me?' (Brennan, 2001). This is what Cassell calls a 'confrontation with the self' (Cassell, 2004). Little *et al* suggest that a diagnosis of cancer (and perhaps any chronic illness) sets a person on an existential quest to recapture some meaning and purpose of life (Little et al., 1998). The big questions surrounding mortality and existence that we can bury in our everyday lives were suddenly raised and demanding answers, having an unsettling and distressing effect as people adjusted to their new identity as a cancer patient. Khalili describes very similar transitions in a case study of a brain tumour patient, mirroring the psychological and sociological theory of adjustment in practice (Khalili, 2007). Having time to process these issues and come to terms with one's new circumstances came with adaptation. The themes evident here of changing one's approach and philosophy on life and appreciating relationships with other people and interactions with one's environment and nature were all consistent with the re-evaluation necessary to deal with changing circumstances. The expression of existence and value of one's contribution in terms of the 'goodness of life' and the 'grandness of nature' were signs of positive transitions as found in other studies exploring the end of life (Strang and Strang, 2001, Sand et al., 2009). Examining one's contribution and (re)gaining meaning in one's life has been shown to enhance a person's well-being and senses of dignity and hope at the end of life (Chochinov, 2003, Chochinov et al., 2005).

Discussion of existential issues did not appear to come easily to patients and carers on one side and professionals on the other in most settings. This finding is consistent with existing studies of spirituality in health care and it is argued that more time and support for people to explore these issues would be beneficial (Strang et al., 2001, Murray et al., 2004, Clayton et al., 2005a). I feel that greater awareness and acknowledgement among patients, their relatives and the health professionals involved

in their care can enrich people's meaningful experiences as they live and die with any progressive illness. As previously discussed, providing a supportive environment to process meaning can foster adaptive coping (Strang et al., 2001).

11.2.5.4 Life after losing a loved one

Similar processes of coping appeared at work for carers after their loved one died. Methods such as distraction were clearly evident as people attempted to process their pain. There seemed to be a strong existential pain as carers accepted the death of their loved one and were trying to learn to live without them. Participants in this study described how the process of grieving for their loved one began before their death, a process of gradual loss of function and personality. This finding has been echoed in the existing literature, especially when there has been a change in personality (Adelbratt and Strang, 2000). Those participants that took part in bereavement interviews valued having had previous contact and the interaction of the follow-up interview and some mentioned lack of contact from the health service since their loved one died. This would suggest that bereavement follow-up is vital to support carers (Milberg et al., 2008).

11.2.6 Professionals' views on services

11.2.6.1 Hospital services

Medical professionals working in a hospital setting were largely satisfied that they provided good quality physical care to people diagnosed with a glioma, which was supported by the views of patients and carers here and in the literature (Lepola et al., 2001). The neuro-surgeon's role was perceived to be clearly defined by patients'

surgical needs at the beginning of a person's illness and care was then transferred to the oncology team. The oncology team was aware of the devastating impact of a glioma diagnosis on all aspects of a person's life but did not feel they had the time and perhaps skills to address these holistic issues with people. Evidence from patients, relatives and nurses working in this setting combined with research and theory discussed in this chapter emphasises the need for increased information and psychosocial support for people during their early illness and throughout people's contact with the hospital (Soothill et al., 2001a, Janda et al., 2006). Better recognition of patient distress at this stage is vital and it should be addressed (Ryan et al., 2005, Kelly et al., 2006) as well as the range of emotional reactions and means of coping (Amato, 1991). The feeling of being inexperienced in addressing supportive care issues has been echoed in the literature (Ryan et al., 2005). While Ryan *et al* also report that doctors do not see addressing distress as their role, I deduced from many health, health-related and social care professionals that they were well aware of the gap in provision of psychosocial support and it was not necessarily that they didn't see it as their role (although this was certainly the case for some) but were not sure how best to address this with patients within the constraints of time. However, effective communication need not be time consuming (Sepucha et al., 2000). Appropriate communications training could enable those working closely with patients and relatives during their contact with the hospital to have the confidence and skill to better address these needs as part of a multi-disciplinary team. All health professionals are well placed to provide supportive care and this dimension of service provision should be developed (Davies and Hopkins, 1997b, Taillibert et al., 2004). Psychological services are available to provide additional support and intervention in cases of enduring maladaptive adjustment and indeed better use should be made of available services. However, basic emotional support has been shown to be a key part of the *normal* adjustment to such a devastating diagnosis and it needs to come from the core team caring for glioma patients. This is not a new finding (Davies and Hopkins, 1997b, NICE, 2006b), but the change has yet to be

integrated into standard service provision. This will also require a cultural shift toward a more holistic view of patient care for some professionals.

The biggest change since Davies *et al*'s guidelines for improving care for brain tumour patients is the advent of the neuro-oncology specialist nurse, which has had a very positive impact on services but is yet to be provided in every UK cancer centre. Many of the professionals interviewed felt that supportive care in the hospital setting was deferred to the specialist nurse in neuro-oncology. It was clear from patient, carer and professional interviews just how much this role was valued and relied upon for all aspects of continuity of care and support for patients and their families. This sentiment is echoed in descriptions and evaluations of the specialist nurse function (Leavitt et al., 1996, Sardell et al., 2000, Curren, 2001, Spetz et al., 2005, Voogt et al., 2005). Problems with the role of the specialist nurse have been identified (Willard and Luker, 2005). Professionals interviewed in the present study were cautious that the specialist nurse was over-relied upon and there were some concerns about the involvement of the nurse over time, particularly once the majority of a person's care had shifted into the community. Further work needs to be carried out to better understand this shift and how continuity of care can be ensured. There is potential for either gaps or overlap of services as it was not clear who was responsible for supporting patients in the community. A community-based nurse may be the optimal way to provide supportive care (Howell et al., 2008). There was variation in continued contact with the hospital specialist nurse dependent on a number of factors with personal relationships forged, troubling medical problems and proximity to the hospital all influencing the likelihood of continued contact with the specialist nurse. However, this was not consistent and a formal protocol of care across the hospital to community divide could be developed to make best use of the community team and ease the pressure on the role of the hospital specialist nurse.

11.2.6.2 Primary and community care services

Primary care professionals were aware of the distinctive issues for glioma patients: prognosis, rarity of the disease, complexity of symptoms, use of steroid therapy and profound problems with physical and cognitive function, setting it apart from other cancers (Taillibert et al., 2004). There was a feeling of lack of competence in dealing with brain tumour patients as a result of this, and so communication links with neuro-oncology and palliative care specialists were paramount to facilitate best practice. Combined with evidence in the present study and in existing research that more education for patients and carers is needed about what to expect and how to deal with medications (Khalili, 2007), this dimension of the GP's role could be developed. GPs had varying degrees of involvement in caring for glioma patients and their families dependent on how ill the patient was; their stage of treatment; perceived patient preference; and an assumption that the hospital team were coordinating their care. The role of primary care in looking after glioma patients has not been previously explored, so these findings provide important insights.

There is room for increased involvement of primary care in the provision of non-specialist palliative care. An issue that was flagged up as a potential stumbling block to providing timely palliative care in the community was willingness to discuss end of life issues and decisions. GPs' discussion of end of life issues varied considerably dependent on their patient's current status. In cases where the patient had deteriorated quite markedly and required extra care in the way of district nursing and specialist palliative care involvement, they were more likely to be involved in discussions and coordination of this type of care. In other cases, both GPs and families were resistant to these discussions. Formal support for carers with an allocated doctor is recommended to ensure that carers are not struggling on alone and being missed until a crisis arises (Salander and Spetz, 2002). Evidence that professionals were not willing to have

discussions on sensitive topics around end of life care suggests that there is work to be done in boosting confidence and competence in this area (Strang et al., 2001, Clayton et al., 2005a). A small but significant number of professionals in the primary care setting raised the subject of the Gold Standards Framework and were attempting to follow the principles of palliative care so there was evidence that this dimension of the service was developing. However, a recent audit of palliative care throughout Scotland suggests there is a long way to go (Audit Scotland, 2008). The research literature reports a need for more specialist palliative care training and support for generalist staff working in hospitals, care homes and in the community as well as more research to understanding the end of life period (Shipman et al., 2008a, Murray et al., 2008).

Shift from secondary to primary and community care

A clearly perceived shift was found from secondary to primary and community care once a person's active treatment was over, particularly for those working in the community setting. As previously raised, there are important implications for better coordination and continuity of care across this divide, as has been previously recommended (Davies and Hopkins, 1997b). Continuity of relationships and reassurance are important to patients (Amato, 1991, Salander, 2002). There was not a system in place for an official hand over to primary and community care as there was no official end to the person's treatment at the hospital. The complexity and unpredictability of gliomas means it was uncertain whether patients needed regular contact with the hospital. In cases of long periods of stability or quick deterioration where no contact with the hospital was necessary, there was no designated coordinator of care, despite someone perhaps naturally taking on that role. It varied from case to case and depended on individual personal relationships with local health care professionals. A proactive GP or a supportive palliative care nurse could coordinate care, but there was no clear strategy identifying such an individual. Further exploration

of this crucial period in a person's illness trajectory is required to develop and plan flexible services to reflect individual need.

11.2.6.3 Specialist palliative care services

Specialists in palliative medicine and nursing in particular viewed supportive care as central to their role and were more comfortable with their ability to provide it, consistent with patient and carer reports and existing findings (Clayton et al., 2005a). However, as previously mentioned, patient and carer reports suggested that palliative care provision was not consistent or a big part of their perceived care in the early phase of their illness. Professionals' biggest concern in relation to specialist palliative care services centred on the provision of timely and appropriate care. Hospital palliative care specialists did not feel they were being used effectively and so there was room for better integration of palliative specialists into standard care for glioma patients, in line with the NICE guidelines (NICE, 2006a).

Moreover, there was scope for earlier involvement of the palliative care team both in the hospital and community setting to assist with controlling symptoms where necessary in addition to the provision of supportive care and the building of relationships that facilitated timely discussion of end of life issues. Early referral to palliative care services has been flagged up as important to ensure the best care for glioma patients (Davies and Hopkins, 1997b). Furthermore, early involvement provides more timely support for carers (Grbich et al., 2000). Evidence from interviews in the present study suggested that timely involvement was dependent on staff feeling able to suggest it and patients' willingness to accept it early in their illness.

The advent of palliative care registers and sustained development of primary care services to include the principles of the Gold Service Framework should also mean that

supportive and palliative care in the community continue to improve as part of the overall 'Living and Dying Well' strategy (Department of Health, 2007)(Scottish Executive, 2008). Further research into these initiatives is needed to fully appreciate their impact over time.

11.2.6.4 Out of hours services

The effective running of out of hours services was a concern to some community care practitioners such as district nurses and specialist palliative care nurses as well as those working in acute medicine. The overriding concern was that glioma patients were not receiving appropriate specialist palliative care when accessing out of hours services, which automatically diverted them to NHS24 when they called. While some services offered a 'special note' to provide important information about the patient's history and needs so they could be triaged quickly and appropriately, in many cases these were not available or out of date so patients ended up being admitted to general emergency wards. Not only was this an inefficient use of services but caused distress for the patient and their families. There was also concern that informal carers were calling NHS24 out of hours due to panic when something went wrong at home. This would suggest that better support and information for people caring for their loved ones at home, already pointed out as a necessary improvement, would alleviate a needless distressing outcome to some degree. Informing patients and carers about procedures for out of hours care and providing them with direct contact numbers would also avoid such problems; again these were all issues identified in patient and carer interviews in this Scottish study and elsewhere (Worth et al., 2006). Out of hours nursing services need to be adequately resourced and universally established and built into an out of hours protocol. Better access to out of hours services was listed as an area for improvement in Audit Scotland's recent audit of palliative care services in Scotland (Audit Scotland, 2008). The need for improved and more appropriate palliative care

being provided within hospitals day and night has also been identified (Worth et al., 2006).

11.2.6.5 Communication and information

Issues surrounding communication and information featured as highly in professional interviews as they did in patient and carer interviews and were, along with increased resources, perceived as the key to improved services. Lack of information provided to patients and carers and the significance of the way in which it was communicated was a top priority for patients and carers. These were a present albeit lesser priority for staff. Problems with providing adequate information to patients and carers were reported to revolve around resources to enable staff to provide support. Lack of time and skill in communicating effectively about sensitive topics such as end of life care were also reported, as has been previously discussed and identified as problematic (Clayton et al., 2005a). There are implications for communications training among non-palliative care specialists to enable them to address sensitive issues and feel competent in providing the support patients and carers require.

Professionals reported good overall communication within their own teams but cited communication breakdown between settings as preventing effective care. Davies *et al* place great emphasis on multi-disciplinary team working and communication in order to meet patients' and relatives' needs and improve the services offered to them (Davies and Hopkins, 1997b). Unfortunately, these guidelines have not been formally applied to services for glioma patients across the country and their impact has not been evaluated. The present study of glioma patients highlighted issues of concern for patients in a Scottish cancer centre over ten years on from Davies *et al*'s study, and provided evidence that many of the key recommendations stand as the improvements have yet to be fully implemented.

A growing literature has addressed the need for communications training in addition to reporting on methods and outcomes and, although they are not without their problems, there is certainly scope for such programmes to be implemented in the neuro-oncology setting (Fallowfield et al., 1998, Fallowfield, 2005, Girgis and Sanson-Fisher, 1998, Gysels et al., 2004, Gysels et al., 2005).

11.2.6.6 ‘Total’ care

There were mixed views about whether or not ‘total’ care should be within the remit of health and social care providers caring for glioma patients. Some felt that this was not possible nor should it be an aim. On the other hand, other practitioners felt that we should strive to address the multiple dimensions of the illness experience. There was also some discussion about how all encompassing total care should be and there was certainly ambiguity remaining about its working definition. I am in agreement with Davies *et al*, who argue that professionals should consider the holistic impact of diagnosis for patients and carers (Davies and Hopkins, 1997b).

Part of total care was the provision of existential and/or spiritual support. As previously found and discussed in relation to existential issues in section 11.2.5.3, spiritual or existential problems were not part of the vocabulary of most patients, carers or professionals interviewed (Strang et al., 2001). Those working in specialist palliative care were more likely to discuss this dimension of care and the chaplaincy service clearly reported their potential role in giving this kind of support to people. However, not being recognised as a full member of the multi-disciplinary team and lack of referrals meant that formal spiritual/existential support was lacking. Greater input from pastoral care is needed, echoing the current direction of Scottish policy on spirituality in health care (NHS Education for Scotland, 2009). The benefit to patients and carers from

this kind of support is evident in relation to their positive adjustment to living with glioma, or any other life-limiting illness (Murray et al., 2003, Grant et al., 2004). As part of improved communication, all professionals stand to gain the awareness and skills to address spiritual or existential needs.

11.2.6.7 Supportive care

Good quality appropriate supportive care has already been highlighted in this thesis as very valuable although sometimes absent. Problems with providing this, related to resources, competence and communication skills, have been discussed in relation to services provided in all settings. While many professionals saw emotional support as a central part of their role in caring for people with a glioma, this was not always the case and there was a need for increased awareness of the importance of this dimension of care, particularly in hospitals where resources were tight and care was focused on the physical. Supportive care is a broad term and encompasses a range of psychosocial issues including information and reassurance, to more active addressing of emotional and adjustment issues. While many professionals did not feel they had the time to deal with the latter, better information and training in competence to communicate in a positive and reassuring manner, responding to patient or carer cues, could provide the level of support that service users expect and wish for. Increased involvement of allied health and social care professionals could also help people address parallel issues such as maximising potential through rehabilitation and dealing with financial concerns. The need for increased research and evaluation of interventions to improve psychosocial care for people with a glioma has been put on the research agenda (Catt et al., 2008).

11.3 Summary and integration of patient, relative and staff views

The views of patients and their relatives did not always converge with those of the health and other professionals interviewed. The kind of language used and the style and focus of interviews varied considerably between the two groups. Patients and relatives did not think in terms of services offered and did not separate symptoms experienced from their emotional reaction and place in their wider personal and social environment. Professionals were, as expected, more service-focussed. There was enormous variety in the themes identified in staff interviews, with those working in the primary, community and social care having a more multi-dimensional view of people's needs. However, there were a number of common issues identified in the two sets of interviews that can usefully be combined. Patients' and relatives' views can also provide an additional insight for staff members to learn from, generating increased awareness that can be translated into improved practice.

During the period leading up to diagnosis, there were not many common issues shared in patient/ relative and professional interviews. However, the pace of the patient's illness during this phase was mirrored in both sets of interviews. Patients and relatives sometimes described a slow process to reaching diagnosis, often the source of distress and frustration. Some patients were waiting for further investigations when a crisis event overtook scheduled tests and led to an emergency admission upon when the tumour was detected. For others, they became suddenly unwell out of the blue and presented to emergency services, by-passing their GP. Professionals' interviews reflected these pathways to diagnosis. GPs described the rare occurrence of glioma and the fact that they felt inexperienced in the management of them. The distinctive, complex and varied symptomology of gliomas was also reported in staff interviews. Staff told of how glioma tended to affect younger people resulting in more complex

handling of issues surrounding work, finances and family life. The devastating prognosis and fast progression of high-grade gliomas was also portrayed. This description of gliomas rarely presenting and the perceived lack of skill in this area could go some way to explaining delayed diagnosis. Upon diagnosis the protocol for treatment was well established and reflected patients' and relatives' experiences of things moving very quickly once they were diagnosed. The experience of physical, cognitive and behavioural symptoms reported by patients and relatives in the lead up to diagnosis can provide a useful insight for GPs working in this area to help detect unusual symptoms and understand patients' experiences as a whole.

Issues around coping and support were central to patient and relative accounts of the experience of living with glioma, but mentioned less by staff members despite an awareness of the issues faced. The insight gained here about the immense emotional reaction to a diagnosis of glioma and the strategies employed to deal with it are extremely valuable for professionals working closely with these patients and their families. Talk of supportive care was much more common in cases where the professional's role was designated to meet supportive care needs specifically either in part (e.g. specialist nurse, community palliative care nurse) or as a whole (e.g. social worker, psychologist). Supportive care needs were not always recognised by those working in acute medicine or were not considered to be part of their role, preferring to leave these needs to other members of the multi-disciplinary team. For example, enormous emphasis was placed on the role of the specialist nurse by staff and was valued greatly by patients and relatives. However, key patient and relative requests for improved information and communication in addition to the need for positive reassurance and hope suggests that those focused on the medical needs of patients should also consider multiple dimensions of care. Better information, communicated appropriately, appears to be closely linked with people's ability to cope and, along with recognition of the emotional issues facing patients and their relatives, was central to

patient care provided by all members of the multi-disciplinary team. One of the key problems reported by informal carers living with the effects of glioma on their loved one was the issue of personality and behavioural change induced by the tumour. While this issue was recognised by health professionals, it was clear they were not aware of the extent of the difficulty this caused for people or carers' need to understand what to expect and how to deal with changes. On the whole, the important role for family carers was recognised by the staff interviewed. The need for support for carers and the opportunity for respite were discussed by those working in primary and community care in particular although it was explained that it was not always possible to provide for this.

The topics of information and communication dominated patient/ relative and professional interviews and were perceived as the key to improving services. Patients and their relatives described a chronic lack of information, starting from before and around the time of formal diagnosis when distress, anxiety and uncertainty were at a peak. There was a desire for increased information that was clear and honest but responsive to people's needs at a particular time and delivered in a sensitive manner. There was a tension between wanting to be fully informed and not wanting to hear devastating news. There was also wide variation in information needs, with some patients and relatives wishing to know more detailed information about glioma and its effects and prognosis whereas others were not ready to hear this, preferring instead to know the process of what would happen to them/ their loved one as a patient in the health care system. It was clear from accounts given from staff working in the acute setting that adequate information and accompanying reassurance and support was not provided to patients and their relatives. Some staff did not see this as their role or it was suggested that they did not know how best to communicate sensitive information, leaving it to other professionals. Patients and relatives were also aware of the lack of joined up communication between professionals, particularly between primary and

secondary care, and the breakdown in continuity and quality of patient care that ensued. These problems were echoed in professional interviews and the need for better communication between professionals was recognised, although it was thought that communication between teams worked well.

The impact on people's lives evident in the accounts given by patients and their relatives was profound. Living with the physical and cognitive effects of the tumour in addition to its emotional devastation and impact on personal, social and work lives was intensely difficult for the patient themselves, and those closest to them. Patients described the loss of their independence and dignity as their illness progressed and family carers struggled to watch their loved one become more ill and provide for increasing care needs. The sheer devastation and loss caused by a diagnosis of glioma on all dimensions of people's lives was widely recognised by the staff caring for patients, especially allied health professionals and nurses working closely with patients to meet supportive care needs. Despite the difficulty of these issues being accepted among staff, there appears to be a requirement for increased awareness and acknowledgement of these issues in addition to provision of appropriate care and support, with staff conceding that it was not possible to provide for all of patients' and relatives' needs.

Talk about death and dying, including fears, uncertainty and questions, were present in patient narratives, sometimes from before a confirmed diagnosis. Other patients were not able to voice their fears and made inexplicit references or avoided the topic all together. Professionals interviewed did not focus on the subject of discussing death with patients and their families, except those working in specialist palliative care. There was a keen awareness among those working in palliative care settings of the importance of timely and appropriate end of life care and a commitment to the Gold Standards Framework was mentioned by some people working in primary care.

However, there was perhaps not awareness of how early on some people were willing to talk about death and dying and had specific questions about their end of life, causing distress while they remained unresolved. Some patients and relatives showed a willingness to have conversations about death and end of life issues such as place of care and sought information about what people could expect from glioma as it progressed, sometimes very early on in patients' illness trajectory. Health professionals lacked confidence in their ability to communicate issues of death and dying, and needed greater confidence in having these discussions and flexibility in attuning to individuals' needs. Another issue common to both patient/ relative and professional interviews was caring for people at the end of their lives, particularly those who were being cared for at home. Staff described practical problems and lack of efficient communication resulting in difficulty keeping patients at home in addition to poor out of hours care. This was mirrored in the narratives of family carers, who described a lack of information about what to expect and how best to care for their loved one as well as not knowing who to contact in an emergency.

Patients did not easily verbalise that spiritual or existential issues were important to them but it was evident that many people had considered some of the big existential questions about life and death as they tried to make sense of their experience, changing the way they viewed themselves and their future. Provision of existential or spiritual support was minimal for glioma patients unless patients actively practised a religious faith and were part of their local church community. Hospital chaplains described practical problems in providing spiritual care to hospital in-patients and were not full members of the multi-disciplinary team. There was very little talk of spiritual or existential care from other health professionals.

A number of significant issues, centring on good communication and information provision, are common in both patient/ relative and professional interviews. There was

often recognition that improvements were needed but little available resources. A number of recommendations based on the findings outlined in this thesis combined with suggestions from patients, relatives and professionals are presented in the final chapter to follow.

Chapter Twelve: Conclusions, future directions and suggested priorities

Exploring the illness trajectory of people with a suspected and subsequently confirmed diagnosis of malignant cerebral glioma gave important insights into the changing experience of patients and carers as they encountered new physical, social, psychological and existential challenges. Serial interviews gave a rich perspective on the subjective experience shared by patients and their relatives and highlighted their most important concerns. Patients and their relatives were, on the whole, positive about their experience of treatment and care over the course of their illness. Staff, in particular, were praised highly by a number of participants, with certain exceptions where specific negative incidents had occurred. Patients and relatives identified lack of information, reassurance and support, particularly in the pre-diagnosis phase, as key areas where they felt supportive care was lacking. The role of the specialist nurse in providing support was widely valued by all patients and relatives but the involvement was not always possible before a confirmed diagnosis had been given or after the treatment phase was over. Varied involvement of primary care and community palliative care services was also suggested in patient, relative and professional accounts, which could result in gaps in supportive care. Lack of information and improved communication were critical themes that linked patient, carer and staff interviews as the key to improving supportive care further. Information, communication, and support were vital to patients in adjusting their lifestyle to accommodate change and learn to live with, and prepare to die from, glioma. These themes centred on successful coping and maintaining hope.

Existing research and policy in England has recognised the multiple dimensions of the experience of glioma (Davies and Hopkins, 1997b, NICE, 2006a). Services have evolved

and focussed more on palliative and supportive care over the years, and there is scope for further in-depth research to understand if and how patients' holistic needs are being met. Furthermore, the impact of broader palliative care policy developments and initiatives in Scotland such as the End of Life Care Strategy including the rolling out of the Gold Standards Framework, Advanced Care Planning and Liverpool Care Pathway, remain to be seen (Department of Health, 2008).

As treatment options continue to develop, people may live longer with even the most aggressive gliomas, and so services need to adopt a holistic approach to care in order to support people long term, often in the community. Recognising the dynamic multi-dimensional distress experienced by patients and their relatives over time is central to the development of sensitive and responsive supportive care (Davies and Higginson, 2003). This approach is also reflective of the patient-centred ethos of care underpinning this thesis, a sentiment resonant in wider health policy ('Better Health, Better Care', The Scottish Government, 2007). There is also need for continued research on these wider issues to complement ongoing clinical trials (Catt et al., 2008).

While some of the findings and hence recommendations are characteristic of people with gliomas and other brain tumours, other issues are generic and may be relevant to people with other aggressive cancers and rapidly progressive illnesses. This is an important finding and has implications for the kinds of interventions that may work to improve cancer services more broadly. However, it is important to remember that this study is as an exploration of the issues facing people living with glioma, and is intended as a platform for further research and specific interventions to assess improvements in perceived supportive care. There are potential implications, subject to this further research and intervention, for health services, policy, teaching and training and includes messages for future patients and carers themselves. A number of priorities

for services to consider, formulated in the discussion chapter 11 and in some cases suggested by patients, relatives and professionals directly, are highlighted below.

12.1 Future research and interventions

A number of areas have been identified in this thesis, suggesting directions for future research and tested interventions to potentially expand and improve services for people affected by glioma as well as other life-limiting progressive illnesses. Recommendations for research include:

- **Focus groups** to be held with groups of health, health-related and social care professionals to consider the priorities for services set out in this thesis; and to brainstorm specific quality improvements to trial and evaluate in different settings to improve patient and carer experience.
- Information from the present study could inform the design of a supplementary **questionnaire** to ascertain the views of a larger number of neuro-oncology patients, to gain information on the number of people throughout the UK whose experiences match those of the participants in this study, to inform subsequent nationwide interventions to improve care.
- An **intervention** to provide and **evaluate** new information booklets that include information about psychosocial and supportive care issues in living with a glioma will give further insight into the effectiveness and acceptability of such information.
- A **qualitative longitudinal study** focusing on the last few months and weeks including the terminal phase for people with a diagnosis of glioma could help redress the difficulty in capturing this period.

- A **qualitative longitudinal** exploration of the separate experience of low-grade glioma patients is warranted, especially highlighting differences in the 'life after diagnosis' period.
- Research to gain a greater understanding of the shift from secondary into primary and community care could help to establish whether a keyworker should be responsible for continuous care throughout a person's illness or whether this person, most likely the clinical nurse specialist, should vary according to the setting in which the patient is being cared for. A **mixed methods** approach to this service evaluation may be most appropriate.
- A study of the lines of communication between secondary and primary care in the coordination of care for glioma patients is required to identify problematic aspects of the system. There is potential here for **action research** to evaluate the use of technology, such as email, to speed up discharge summaries and provide an open line of contact for specialist advice.
- Increased understanding in a **qualitative exploration** of the role and benefit of routine existential support from **hospital chaplains and palliative care specialists** would inform the future development of these services, with potential training and policy implications.

12.2 Suggested priorities for services

Potential areas are identified from this in-depth exploratory study, for the expansion and development of services to provide for the needs of glioma patients and their relatives, subject to further research as highlighted above.

12.2.1 Possible developments to increase provision of support for patients and relatives

- While patient and relative accounts indicated that many professionals displayed great sensitivity to and awareness of their needs, there is suggestion that some **professionals** could display an increased awareness of and sensitivity to people's normal emotional reactions and distress from the pre-confirmed diagnosis phase of their illness onwards, and acknowledge to patients how difficult this time can be; with communications training to support this (see section 12.4).
- As highlighted in patient, relative and professional interviews, greater discussion and liaison is required from early in the illness trajectory between professionals in hospitals and primary care (**neurosurgical team and GPs**) and with patients and their families to determine information and supportive care needs.
- Provision of procedural information on what to expect, communicated by **all professionals** and particularly during the pre-diagnosis and treatment phase of the illness, is indicated as a priority for patients and relatives, particularly in the pre-diagnosis phase.
- Patient Concerns Inventories (PCIs)(e.g. Rogers et al., 2009) could routinely be completed before each consultation – already piloted in the study hospital – in the **neuro-oncology clinic** to address the issue of appropriate and timely information and support highlighted in patient and relative accounts, in order to provide a structure to help elicit what kinds of information and support people want, as part of a larger randomised controlled trial to assess their effectiveness.

12.2.2 Possible developments to facilitate better information and recognition of information needs

- It is suggested that **all health professionals** recognise the tension that patients and their relatives may experience between wanting to know and not wanting to know identified in patient and relative accounts of seeking information, in order to guide consultations and ensure responsive provision and appropriate support.
- Awareness among **all health professionals** of the strong link between information and coping, and understanding of the processes of normal adjustment, could be used to guide consultations and provision of support.
- Patients and relatives valued recognition and acknowledgement by **all health professionals** of the importance of reassurance and hope and the provision of a safe context in which to cultivate it, with implications for ensuring this form of support is given.
- Provision of developed information leaflets or booklets in **Scottish centres of neuro-oncology**, as outlined in relation to research, to include more about the social, psychological and practical dimensions of living with a glioma could improve patient perceived supportive care (these are currently being developed by The Scottish Adult Neuro-oncology Network (**SANON**) and it is hoped the current thesis can inform and support their ongoing development).
- The provision within the above information booklets or a separate written record for logging drug regimes (e.g. steroids, anti-convulsants), and any changes made, was highlighted as a concern for relatives in particular and should be evaluated.
- **All health professionals** should provide information that is tailored to individuals through use of the above information leaflets and targeted communication skills, as suggested in patient and relative interviews.

- Interviews with professionals suggest that leaflets or a downloadable online resource containing relevant practical information about glioma for non-specialist professionals, including use of steroids, would be beneficial for **GPs**.
- Professional interviews also indicate that better use of technology is required (fax, telephone and secure email) to minimise delay in sending information between **hospital and community** settings. A pro-forma filled out after clinics by the neuro-oncology team and faxed or emailed to update primary care teams and out of hours providers could be considered and evaluated to ease communication with key allied health professionals copied into all documentation.
- Interviews with relatives identify their need for increased information and support from the hospital **neuro-oncology and community teams**, particularly information on what to expect; what to do in an emergency; details of medications and how to monitor them; and support to understand and deal with personality and behavioural changes, in the form of verbal and written information.

12.2.3 Possible developments for services

- Improved appropriate *evidence-based* **out of hours services** are indicated as a priority in professional interviews, with 'special notes' on glioma patients, updated by **hospital and community** practitioners.
- Consideration of early referrals by **all professionals working in neuro-oncology** to the **hospital palliative care team** is suggested for more specialist and appropriate care in the acute setting.
- Reflected in patient, relative and professional interviews, greater inclusion of **Allied Health Professionals** could help to set goals with patients and help them

maximise their 'time of everyday life' and potential to lead a 'new normal' life and thus increase well-being.

- Better support for and development of the **specialist nurse** role should be considered , with resource implications as well as sharing supportive care across multi-disciplinary teams, where patients, relatives and professionals suggest it is lacking.
- Further research could inform the coordination, by **hospital and community** teams, of the shift from secondary to community care, with an intervention to evaluate a designated practitioner responsible for overall coordination of care throughout the whole illness.

12.3 Messages for future patients and carers

A number of messages directed at patients and carers themselves are suggested to encourage people to make their needs known so that they can be identified and addressed.

- Patients and carers should **voice concerns** of whatever nature to any member of staff, so that **any difficulties or supportive care needs** can be identified and addressed.
- Patients should be enabled to let the staff know if they want **more information**, and **what type of information** they might want, either about services in general, or more specific information about the progress of their illness and what the future might hold.
- Patients and relatives should be encouraged to raise **any questions** they have, including existential questions about the meaning or purpose of life, that are

causing worry or distress. Raising these and **discussing them with staff** can benefit people and help them feel their support needs are acknowledged.

12.4 Suggested priorities for policy

A number of areas for potential policy changes, again subject to further investigation, have been suggested to expand services and provide the necessary funding and legislation to implement many of the suggestions outlined in this chapter.

- Increased **funding allocated** at a local level to enable the **provision of supportive care** as part of mainstream health care may be needed to fund communications training, better information provision and better access to psychological services where appropriate.
- An evaluation of a **patient summary for out of hours care** throughout Scotland for glioma patients and anyone on the palliative care register could lead to wider funding for their provision. These are currently being introduced electronically in all Lothian GP practices, and updated daily.
- Funding may also be required for a **formal evidence-based protocol** in Scotland for the outreach or formal **handover from secondary into primary care** to ensure continuous supportive care, based on further research to understand the complexity of this transition.
- **An exploration of potential funding** for the provision of community-based residential care in Scotland for glioma patients with complex needs under 65 with significant care demands is required.

12.5 Teaching and training

Many of the suggestions outlined in previous sections have implications for teaching and training to develop the appropriate skills to meet the information and support needs indicated in patients and relative interviews, in addition to improving communication among professionals.

- **Communications training** *based on the latest evidence* of effective training interventions **for all staff** caring or who might care for people with a diagnosis of glioma will help increase awareness of the multiple dimensions of the illness experience and give confidence to recognise and acknowledge distress and provide support to patients and their families.
- Further **communications training for all staff** could improve liaison with other members of a multi-disciplinary team and those working in different settings, also *based on evidence of effective training* interventions.
- **Patient and relative care could be improved by further professional training** in the ability to recognise acute anxiety, depression, adjustment disorders or existential distress and consideration of appropriate management and early referral to psychological services when required.

Glossary of terms

A2 – Astrocytoma grade II – a form of glioma

AA3 – anaplastic astrocytoma grade III – a form of glioma

Anaplastic oligodendroglioma (grade III) – an intermediate grade glioma

Assumptive worlds – A cognitive theory in psychology describing a person's set of core cognitive assumptions about themselves and the world they live in (Parkes, 1971)

Beneficence – the act of benefiting another or doing good

Biographical disruption – a theory developed by Bury (1982) to describe the disruptive impact of illness on people's lives and person

Blunters – A term used in coping theory to describe a person who actively avoids information and has a passive or avoidant coping style based on the Miller Behavioural Style Scale (Miller, 1987)

Cognitive manoeuvres – A psychological theory developed to describe the way people actively manage and reframe their thoughts to view a situation in such a way as to facilitate coping with distressing circumstances (Salander et al., 1996)

Constant comparative method – a technique used in grounded theory to analyse qualitative research by repeated comparison across the data

(Social) Constructionism – the theory that reality is jointly constructed through the interaction of those acting in it and their surrounding context

DCN – Department of Clinical Neurosciences

Dexamethasone – A steroid drug commonly used in neuro-oncology

DGH – District general hospital

Disavowal – This is a coping strategy and form of cognitive manoeuvre to actively block information that is too distressing to think about. A form of conscious self-deception to facilitate adaptive coping (Salander and Windahl, 1999)

DT – Distress thermometer

Dyads – a patient and carer pair

Epistemological - philosophical theory about what can be known about the world

Existential or spiritual – a component of introspection related to meaning and purpose of life

GBM – Glioblastoma multiforme grade IV – the most common and aggressive form of glioma

Grounded theory – an approach to qualitative analysis where theory emerges from close examination of and attention to the data

GSF – Gold Standards Framework

Holistic – multi-dimensional

Interpretive inquiry – an approach to understand and explain a particular phenomenon

Liminality – A sociological theory to describe the marginalisation of individuals with a chronic or life-limiting illness onto a different path or route in their lives. People are thought to undergo a process of transition and existential quest to understand this change in their lives (Little et al., 1998)

Macro – broader social structures in which people are acting

MDT – Multi-disciplinary team

Micro – individual level of experience

Mindfulness – a Buddhist philosophy encouraging the individual to keep their thoughts rooted in the present and attend closely to them without distraction in order to witness them ‘purely’

Monitors – A term used in coping theory to describe a person who actively seeks information and has a proactive coping style according to the Miller Behavioural Style Scale (Miller, 1987)

NHS24 – Scottish telephone triage advice line (English equivalent is NHS Direct)

NICE – National Institute of Clinical Excellence

Non-maleficence – the act of not causing harm to another

NVivo – a ‘computer assisted qualitative data analysis software’ package to manage large volumes of qualitative data

Objectivism – the ontology that reality exists independently of human social interaction

Oligodendroglioma – a form of glioma, usually low-grade (I-II)

Ontological - philosophical theory about the nature of existence

OT – Occupational therapist

Patient involvement or participation – a theory about the empowered patient who plays an active role in discussion and interaction with health professionals and in some cases has an active part in decision-making about their health care

PCV – Procarbazine CCNU and Vincristine chemotherapy drug combination commonly used in neuro-oncology

Positivism – the epistemology that reality is objective and can be studied directly

Preconscious – Not immediately aware of in the conscious mind or actively attended to

Private accounts – access to a more intimate or personal story and thoughts a person may not always choose to share

Public accounts – the story that an individual chooses to tell to a public audience to ensure that they are perceived in a particular way

QLL – qualitative longitudinal

SANON – Scottish Adult Neuro-oncology Network

Subjectivism- the theory that reality is entirely in the mind of the subject and cannot be truly accessed.

T1 – time one

T2 – time two

T3 – time three

T4 – time four

Temodal – a chemotherapy drug commonly used in neuro-oncology

Triads – groups of three linked persons; in this study typically a patient, carer and linked health professional such as GP

References

- ADAM, B. (1995) *Timescapes: the social analysis of time*, Cambridge, Polity.
- ADDINGTON-HALL, J. & ALTMAN, D. (2000) Which terminally ill cancer patients in United Kingdom receive care from community specialist palliative care nurse? . *Journal of Advanced Nursing*, 32, 799-806.
- ADELBRATT, S. & STRANG, P. (2000) Death anxiety in brain tumour patients and their spouses. *Palliat Med*, 14, 499-507.
- AJZEN, I. (1988) *Attitudes, Personality and Behaviour*, Milton Keynes, Open University Press.
- AKIZUKI, N., AKECHI, T., NAKANISHI, T., YOSHIKAWA, E., OKAMURA, M., NAKANO, T., MURAKAMI, Y. & UCHITOMI, Y. (2003) Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. *Cancer*, 97, 2605-13.
- AMATO, C. A. (1991) Malignant glioma: coping with a devastating illness. *Journal of Neuroscience Nursing*, 23, 20-2.
- ANDERSON, S. I., TAYLOR, R. & WHITTLE, I. R. (1999) Mood disorders in patients after treatment for intracranial tumours. *British Journal of Neurosurgery*, 13, 480-5.
- ARONSON, J. (2006) Sometimes, never. *BMJ*, 333: 445.
- ASHBY, M. E. & DOWDING, C. (2001) Hospice care and patients' pain: communication between patients, relatives, nurses and doctors. *International Journal of Palliative Nursing*, 7, 58-67.
- AUDIT SCOTLAND (2008) Review of palliative care services in Scotland. Audit Scotland. http://www.audit-scotland.gov.uk/docs/health/2008/nr_080821_palliative_care.pdf, accessed 10.11.08
- BARBOUR, R. S. (2000) The role of qualitative research in broadening the evidence base for clinical practice *Journal of Evaluation in Clinical Practice*, 6, 155-63.
- BARBOUR, R. S. (2001) Checklists for improving the rigour of qualitative research: a case of the 'tail wagging the dog'? *BMJ*, 322, 1115-7.
- BARBOUR, R. S. (2008a) Research Design. *Introducing Qualitative Research: a student guide to the craft of doing qualitative research*. London, Sage.
- BARBOUR, R. S. (2008b) The Scope and Contribution of Qualitative Research. *Introducing Qualitative Research: a student guide to the craft of doing qualitative research*. London, Sage.
- BARBOUR, R. S. (2008c) Theorising in Qualitative Data Analysis. *Introducing Qualitative Research: a student guide to the craft of doing qualitative research*. London, Sage.

- BARBOUR, R.S. (2008d) Presenting and writing up qualitative research. *Introducing Qualitative Research: a student guide to the craft of doing qualitative research*. London, Sage.
- BARCLAY, S. & ARTHUR, A. (2008) Place of death: how much does it matter? The priority is to improve end-of-life care in all settings. *British Journal of General Practice*, 58, 229-31.
- BEAUCHAMP, T. L. & CHILDRESS, J. F. (1989) *Principles of biomedical ethics*, New York, Oxford, Oxford University Press.
- BECKER, H. S. (1963) *Outsiders: Studies in the sociology of deviance*, New York, The Free Press.
- BRENNAN, J. (2001) Adjustment to cancer - coping or personal transition? . *Psycho-oncology*, 10, 1-18.
- BRITTEN, N., CAMPBELL, R., POPE, C., DONOVAN, J., MORGAN, M. & PILL, R. (2002) Using meta-ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research and Policy*, 7, 209-15.
- BROWN, P. D., BALLMAN, K. V., RUMMANS, T. A., MAURER, M. J., SLOAN, J. A., BOEVE, B. F., GUPTA, L., TANG-WAI, D. F., ARUSELL, R. M., CLARK, M. M. & BUCKNER, J. C. (2006) Prospective study of quality of life in adults with newly diagnosed high-grade gliomas. *Journal of Neuro-oncology*, 76, 283-91.
- BROWN, P. D., DECKER, P. A., RUMMANS, T. A., CLARK, M. M., FROST, M. H., BALLMAN, K. V., ARUSELL, R. M. & BUCKNER, J. C. (2008) A prospective study of quality of life in adults with newly diagnosed high-grade gliomas: comparison of patient and caregiver ratings of quality of life. *American Journal of Clinical Oncology*, 31, 163-8.
- BROWN, P. D., MAURER, M. J., RUMMANS, T. A., POLLOCK, B. E., BALLMAN, K. V., SLOAN, J. A., BOEVE, B. F., ARUSELL, R. M., CLARK, M. M. & BUCKNER, J. C. (2005) A prospective study of quality of life in adults with newly diagnosed high-grade gliomas: the impact of the extent of resection on quality of life and survival. *Neurosurgery*, 57, 495-504.
- BROWN, R. F., BUTOW, P. N., DUNN, S. N. & TATTERSAL, M. H. N. (2001) Promoting patient participation and shortening cancer consultations: a randomised trial *British Journal of Cancer*, 85, 1273-79.
- BRUERA, E. (1994) Ethical issues in palliative care research. *Journal of Palliative Care*, 10, 7-9.
- BURNS, C. M., CRAFT, P. S. & Roder, D. M. (2005) Does emotional support influence survival? Findings from a longitudinal study of patients with advanced cancer. *Supportive Care in Cancer*, 13, 295-302.
- BURY, M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4, 167-82.

- BUTOW, P. N., DUNN, S. N., TATTERSAL, M. H. N. & JONES (1994) Patient participation in the cancer consultation: Evaluation of a question prompt sheet *Annals of Oncology*, 5, 199-204.
- BUTOW, P. N., MACLEAN, M., DUNN, S. M., TATTERSAL, M. H. N. & BOYER, M. J. (1997) The dynamics of change: cancer patients' preferences for information, involvement and support. *Annals of Oncology*, 8, 857-63.
- BYRNE, A., ELLERSHAW, J., HOLCOMBE, C. & SALMON, P. (2002) Patients' experience of cancer: evidence of the role of 'fighting' in collusive clinical communication *Patient Education and Counselling*, 48, 15-28.
- CANCER WEB (1998) Supportive care. <http://cancerweb.ncl.ac.uk/cgi-bin/omd?supportive+care> accessed 02.02.09
- CASSELL, E. J. (2004) *The Nature of Suffering and the goals of medicine*, Oxford, Oxford University Press.
- CATT, S., CHALMERS, A. & FALLOWFIELD, L. (2008) Psychosocial and supportive-care needs in high-grade glioma *Lancet Oncology*, 9, 884-91.
- CHANG, S. M., PARNEY, I. F., HUANG, W., ANDERSON, F. A., JR., ASHER, A. L., BERNSTEIN, M., LILLEHEI, K. O., BREM, H., BERGER, M. S. & LAWS, E. R. (2005) Patterns of care for adults with newly diagnosed malignant glioma. *JAMA*, 293, 557-64.
- CHARMAZ, K. (2006) *Constructing Grounded Theory: a practical guide through qualitative analysis*, London, Sage.
- CHOCHINOV, H. M. (2003) Thinking outside the box: depression, hope, and meaning at the end of life. *Journal of Palliative Medicine*, 6, 973-7.
- CHOCHINOV, H. M., HACK, T., HASSARD, T., KRISTJANSON, L. J., MCCLEMENT, S. & HARLOS, M. (2005) Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology*, 23, 5520-5.
- CLAYTON, J. M., BUTOW, P. N., ARNOLD, R. M. & TATTERSAL, M. H. N. (2005a) Discussing end of life issues with terminally ill cancer patients and their carers: a qualitative study. *Supportive Care in Cancer*, 13, 589-99.
- CLAYTON, J. M., BUTOW, P. N., ARNOLD, R. M. & TATTERSAL, M. H. N. (2005b) Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer*, 103, 1965-75.
- CLAYTON, J. M., HANCOCK, K., PARKER, S., BUTOW, P. N., WALDER, S., CARRICK, S., CURROW, D., GHERSI, D., GLARE, P., HAGERTY, R., OLIVER, I. N. & TATTERSAL, M. H. N. (2008) Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-oncology*, 17, 641-59.
- CORDEN, A. & MILLAR, J. (2007) Time and Change: A Review of the Qualitative Longitudinal Research Literature for Social Policy. *Social Policy and Society*, 6, 583-92.

- CORNER, J. L. & RICHARDSON, A. Cancer Reform Strategy Patient Experience Working Group (2007) *Cancer Survivorship*, MacMillan.
- CORNWELL, J. (1984) *Hard Earned Lives: Accounts of health and illness from East London* London, Tavistock.
- COURTENS, A. M., STEVENS, F. C. J., CREBOLDER, H. F. J. M. & PHILIPSEN, B. (1996) Longitudinal study on quality of life and social support in cancer patients. *Cancer Nursing*, 19, 162-69.
- CRESSWELL, J. W. (2007) Five Qualitative Approaches to Qualitative Inquiry. *Qualitative Inquiry and Research Design: choosing among the five approaches*. Second ed., London, Sage.
- CROTTY, M. J. (1998) *The Foundations of Social Research: meaning and perspective in the research process*, London, Sage.
- CROUCH, M. & MCKENZIE, H. (2006) The logic of small samples in interview-based qualitative research *Social Science Information sur les sciences sociales*, 45, 483-99.
- CURREN, J. (2001) Support needs of brain tumour patients and their carers: the place of a telephone service. *International Journal of Palliative Nursing*, 7, 331-7.
- D'ANGELO, C., MIRIJELLO, A., LEGGIO, L., FERRULLI, A., CAROTENUTO, V., ICOLARO, N., MICELLI, A., D'ANGELO, V., GASBARRINI, G. & ADDOLORATO, G. (2008) State and trait anxiety and depression in patients with primary brain tumours before and after surgery: 1 year longitudinal study. *Journal of Neurosurgery*, 108, 281-6.
- DAVIES, E. & BANNON, M. (1999) Opportunities for improving the quality of care in malignant cerebral glioma. *Journal of Neurology, Neurosurgery and Psychiatry*, 66, 693.
- DAVIES, E. & CLARKE, C. (2004) Early symptoms of brain tumours. *Journal of Neurology, Neurosurgery, and Psychiatry*, 75, 1205-6.
- DAVIES, E. & CLARKE, C. (2005) Views of bereaved relatives about quality of survival after radiotherapy for malignant cerebral glioma. *Journal of Neurology, Neurosurgery, and Psychiatry*, 76, 555-61.
- DAVIES, E., CLARKE, C. & HOPKINS, A. (1996a) Malignant cerebral glioma--I: Survival, disability, and morbidity after radiotherapy. *BMJ*, 313, 1507-12.
- DAVIES, E., CLARKE, C. & HOPKINS, A. (1996b) Malignant cerebral glioma--II: Perspectives of patients and relatives on the value of radiotherapy. *BMJ*, 313, 1512-6.
- DAVIES, E., HALL, S. & CLARKE, C. (2003) Two year survival after malignant cerebral glioma: patient and relative reports of handicap, psychiatric symptoms and rehabilitation. *Disability and Rehabilitation*, 25, 259-66.
- DAVIES, E. & HIGGINSON, I. J. (2003) Communication, information and support for adults with malignant cerebral glioma : a systematic literature review. *Supportive Care in Cancer*, 11, 21-9.

- DAVIES, E. & HIGGINSON, I. J. (2005) Systematic review of specialist palliative day-care for adults with cancer. *Supportive Care in Cancer*, 13, 607-27.
- DAVIES, E. & HOPKINS, A. (1997a) Good practice in the management of adults with malignant cerebral glioma: clinical guidelines. Working Group, Royal College of Physicians. *British Journal of Neurosurgery*, 11, 318-30.
- DAVIES, E. & HOPKINS, A. (1997b) *Improving care for patients with malignant cerebral glioma*, Royal College of Physicians of London.
- DAVIES, E. A., HALL, S. M., CLARKE, C. R., BANNON, M. P. & HOPKINS, A. P. (1998) Do research interviews cause distress or interfere in management? Experience from a study of cancer patients. *Journal of the Royal College of Physicians of London*, 32, 406-11.
- DE RAEVE, L. (1994) Ethical issues in palliative care research. *Palliative Medicine*, 9, 165-6.
- DEAN, R. A. & MCCLEMENT, S. E. (2002) Palliative care research: methodological and ethical challenges. *International Journal of Palliative Nursing*, 8, 376-80.
- DEPARTMENT OF HEALTH (2000) The NHS Cancer Plan: a plan for investment and reform. London: Department of Health.
- DEPARTMENT OF HEALTH (2001) The Gold Standards Framework: A programme for community palliative care. NHS, Department of Health.
- DEPARTMENT OF HEALTH NHS End of Life Care Programme (2007) The Gold Standards Framework Position Paper. Department of Health.
- DEPARTMENT OF HEALTH (2008) End of Life Care Strategy: promoting high quality care for all adults at the end of life.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277, accessed 03.11.08
- DEPARTMENT OF HEALTH (August 2004) Quality and Outcomes Framework. Department of Health.
http://www.dh.gov.uk/en/Healthcare/Primarycare/Primarycarecontracting/QOF/DH_4125653, accessed 04.11.08
- DEY, I. (1999) *Grounding grounded theory: Guidelines for qualitative inquiry*, San Diego, Academic.
- DIXON-WOODS, M., AGARWAL, S., YOUNG, D., JONES, D. & SUTTON, A. (2004a) Integrative Approaches to Qualitative and Quantitative Evidence. Health Development Agency.
- DIXON-WOODS, M., CAVERS, D., AGARWAL, S., ANNANDALE, E., ARTHUR, A., HARVEY, J., HSU, R., KATBAMNA, S., OLSEN, R., SMITH, L. K. & SUTTON, A. J. (2006) Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6 (1): 35-48.

- DIXON-WOODS, M., SHAW, R. L., AGARWAL, S. & SMITH, J. A. (2004b) The problem of appraising qualitative research *Quality and Safety in Health Care* 13, 223-5.
- DURITY, M. B., WYNESS, M. A., DURITY, F. & RATEL, M. (2000) Codman award paper. Education and information needs identified by patients and key family members prior to surgery for a skull base neoplasm: implications for practice. *Axone*, 22, 32-45.
- EDVARDSSON, T. & AHLSTROM, G. (2005) Illness-related problems and coping among persons with low-grade glioma. *Psychooncology*, 14, 728-37.
- EDVARDSSON, T., PAHLSON, A. & AHLSTROM, G. (2006) Experiences of onset and diagnosis of low-grade glioma from the patient's perspective. *Cancer Nursing*, 29, 415-22.
- EDWARDS, A., ELWYN, G., HOOD, K. & ROLLNICK, S. (2000) Judging the 'weight of evidence' in systematic reviews: introducing rigour into the qualitative overview stage by assessing signal and noise. *Journal of Evaluation in Clinical Practice*, 177-84.
- ELIOTT, J. & OLVER, I. (2002) The discursive properties of "hope": A qualitative analysis of cancer patients' speech *Qualitative Health Research*, 12, 173-93
- EXLEY, C., FIELD, D., JONES, L. & STOKES, T. (2005) Palliative care in the community for cancer and end-stage cardiorespiratory disease: the views of patients, lay carers and health care professionals *Palliative Medicine*, 19, 76-83.
- EXPERT ADVISORY GROUP ON CANCER (1995) A policy framework for commissioning cancer services. London and the Welsh office: Department of Health.
- FAITHFULL, S., COOK, C. & LUCAS, C. (2005) Palliative care of patients with a primary malignant brain tumour: case review of service use and support provided. *Palliative Medicine*, 19, 545-50.
- FALLOWFIELD, L. (1993) Giving sad and bad news. *The Lancet*, 341, 476-8.
- FALLOWFIELD, L. (2001) Participation of patients in decisions about treatment for cancer. *BMJ*, 323 (7322): 1144.
- FALLOWFIELD, L. (2005) Learning how to communicate in cancer settings. *Supportive Care in Cancer*, 13, 349-50.
- FALLOWFIELD, L., FORD, S. & LEWIS, S. (1995) No news is not good news: information preferences of patients with cancer. *Psychooncology*, 4, 197-202.
- FALLOWFIELD, L., LIPKIN, M. & HALL, A. (1998) Teaching senior oncologists communication skills: results from phase I of a comprehensive longitudinal program in the United Kingdom. *Journal of Clinical Oncology*, 16, 1961-8.
- FALLOWFIELD, L. J., JENKINS, V. A. & BEVERIDGE, H. A. (2002) Truth may hurt but deceit hurts more: communication in palliative care. *Palliative Medicine*, 16, 297-303.

- FERREL, B. & GRANT, M. (2001) Nursing Research. IN FERREL, B. A. C., N. (EDS) (Ed.) *Textbook of Palliative Research* Oxford, Oxford University Press.
- FESTINGER, L. (1954) A theory of social comparison processes. *Human Relations*, 7.
- FINLAY, L. (2002) Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2, 209-30.
- FOX, S. & LANTZ, C. (1998) The brain tumor experience and quality of life: a qualitative study. *Journal of Neuroscience Nursing*, 30, 245-52.
- FRANK, A. W. (1995) *The Wounded Storyteller: body, illness and ethics*, Chicago, University of Chicago Press.
- FRIEDRICHSEN, M. J., STRANG, P. M. & CARLSSON, M. E. (2000) Breaking bad news in the transition from curative to palliative care - patient's view of the doctor giving the information. *Supportive Care in Cancer*, 8, 472-78.
- FUNK, L. M. & STAJUHAR, K. (2009) Interviewing Family Caregivers: Implications of the Caregiving Context for the Research Interview. *Qualitative Health Research*, 19, 859-65.
- GERGEN, K. J. (1973) Social psychology as history. *Journal of Personality and Social Psychology*, 26, 309-20.
- GERRARD, G. E., PRESTWICH, R. J., FRANKS, K. N. & LEVY, D. (2003) Neuro-oncology practice in the UK. *Clinical Oncology*, 15, 478-84.
- GESSLER, S., LOW, J., DANIELLS, E., WILLIAMS, R., BROUGH, V., TOOKMAN, A. & JONES, L. (2008) Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psycho-oncology*, 17, 538-47.
- GILLON, R. (1994) Medical ethics: four principles plus attention to scope. *BMJ*, 309, 184-90.
- GIOVAGNOLI, A. R. (1999) Quality of life in patients with stable disease after surgery, radiotherapy, and chemotherapy for malignant brain tumour. *Journal of Neurology, Neurosurgery and Psychiatry*, 67, 358-63.
- GIOVAGNOLI, A. R., SILVANI, A., COLOMBO, E. & BOIARDI, A. (2005) Facets and determinants of quality of life in patients with recurrent high grade glioma. *Journal of Neurology, Neurosurgery and Psychiatry*, 76, 562-68.
- GIOVAGNOLI, A. R., TAMBURINI, M. & BOIARDI, A. (1996) Quality of life in brain tumour patients. *Journal of Neuro-oncology*, 30, 71-80.
- GIRGIS, A. & SANSON-FISHER, R. W. (1998) Breaking bad news 2: Current best advice for clinicians. *Behavioural Medicine*, 24, 53-9.
- GLASER, B. & STRAUSS, A. (1967) *The Discovery of Grounded Theory*, Chicago, Aldine.
- GLEASON, J. F. J., CASE, D., RAPP, S. R., IP, E., NAUGHTON, M., BUTLER, J. M. J., MCMULLEN, K., STIEBER, V., SACONN, P. & SHAW, E. G. (2008) Symptom clusters in newly diagnosed brain tumour patients. *Journal of Supportive Oncology*, 5, 427-33.
- GOFFMAN, E. (1969) *The Presentation of the Self in Everyday Life*, London, Allan Lane.

- GOMES, B. & HIGGINSON, I. J. (2006) Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*, 332, 515-21.
- GRANDE, G. E., MYERS, L. B. & SUTTON, S. R. (2006) How do patients who participate in cancer support groups differ from those who do not? *Psychooncology*, 15, 321-34.
- GRANT, E., MURRAY, S. A., KENDALL, M., BOYD, K., TILLEY, S. & RYAN, D. (2004) Spiritual issues and needs: perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study. *Palliative and Supportive Care*, 2, 371-8.
- GRANT, R. (2004) Brain tumour diagnosis and management: Royal College of Physicians guidelines. *Journal of Neurology, Neurosurgery and Psychiatry*, 75, ii18-ii23.
- GRBICH, C., PARKER, D. & MADDOCKS, I. (2000) Communication and information needs of care-givers of adult family members at diagnosis and during treatment for terminal cancer. *Progress in Palliative Care*, 8, 345-50.
- GREENHALGH, T. & PEACOCK, R. (2005) Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ*, 331, 1064-5.
- GROSSMAN, P., NIEMANN, L., SCHMIDT, S. & WALACH, H. (2004) Mindfulness-based stress reduction and health benefits. A meta-analysis. *Psychosomatic Medicine*, 57, 35-43.
- GROSSMAN, S. A. & BATARA, J. F. (2004) Current management of glioblastoma multiforme. *Seminars in oncology*, 31, 635-44.
- GUERRERO, D. (2002) Neuro-oncology: a clinical nurse specialist perspective. *International Journal of Palliative Nursing*, 8, 28-9.
- GUPTA, T. & SARIN, R. (2002) Poor prognosis high-grade gliomas: evolving an evidence-based standard of care. *Lancet Oncology*, 3, 557-64.
- GUSTAFSSON, M., EDVARDSSON, T. & AHLSTROM, G. (2006) The relationship between function, quality of life and coping in patients with low-grade gliomas. *Supportive Care in Cancer*, 14, 1205-12.
- GYSELS, M., RICHARDSON, A. & HIGGINSON, I. J. (2004) Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. *Supportive Care in Cancer*, 12, 692-700.
- GYSELS, M., RICHARDSON, A. & HIGGINSON, I. J. (2005) Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care in Cancer*, 13, 356-66.
- GYSELS, M., SHIPMAN, C. & HIGGINSON, I. J. (2008a) "I will do it if it will help others:" motivations among patients taking part in qualitative studies in palliative care. *Journal of Pain and Symptom Management*, 35, 347-55.

- GYSELS, M., SHIPMAN, C. & HIGGINSON, I. J. (2008b) Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Medical Ethics*, 9, 7-13.
- HAGERTY, R. G., BUTOW, P. N. & ELLIS, P. M. (2005) Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *Journal of Clinical Oncology*, 23, 1278-88.
- HAHN, C. A., DUNN, R. H., LOGUE, P. E., KING, J. H., EDWARDS, C. L. & HALPERIN, E. C. (2003) Prospective study of neuropsychologic testing and quality of life assessment of adults with primary malignant brain tumours. *International Journal of Radiation Oncology, Biology and Physics*, 55, 992-9.
- HAMMERSLEY, M. (1992) *What's wrong with ethnography: methodological explorations*, London, Routledge.
- HARRIS, F. M., KENDALL, M., BENTLEY, A., MAGUIRE, R., WORTH, A., MURRAY, S., BOYD, K., BROWN, D., KEARNEY, N. & SHEIKH, A. (2008) Researching experiences of terminal cancer: a systematic review of methodological issues and approaches. *European Journal of Cancer Care* 17, 377-86.
- HEIMANS, J. J. & TAPHOORN, M. J. B. (2002) Impact of brain tumour on quality of life. *Journal of Neurology*, 249, 955-60.
- HOFFMAN, B. M., ZEVON, M. A., D'ARRIGO, M. C. & CECCHINI, T. B. (2004) Screening for distress in cancer patients: the NCCN rapid-screening measure. *Psychooncology*, 13, 792-9.
- HOLLAND, J., THOMSON, R. & HENDERSON, S. Families and Social Capital ESRC Research Group (2006) Qualitative Longitudinal Research: A discussion paper. *Working paper number 21*. London, South Bank University.
- HOPKINSON, J. B. (1999) A study of the perceptions of hospice day care patients: my phenomenological methodology. *International Journal of Nursing Studies*, 36, 203-7.
- HOPKINSON, J. B., WRIGHT, D. N. & CORNER, J. L. (2005) Seeking new methodology for palliative care research: challenging assumptions about studying people who are approaching the end of life. *Palliative Medicine*, 19, 532-7.
- HOWELL, D. M., SUSSMAN, J., WIERNIKOWSKI, J., PYETTE, N., BAINBRIDGE, D., O'BRIEN, M. & WHELAN, T. (2008) A mixed-method evaluation of nurse-led community-based supportive cancer care. *Supportive Care in Cancer*, 16, 1343-52.
- HUANG, M. E., WARTELLA, J. E. & KREUTZER, J. S. (2001) Functional outcomes and quality of life in patients with brain tumours: a preliminary report. *Archives of Physical Medicine and Rehabilitation*, 82, 1540-6.
- HUGHES, C. & DUNN, J. (2002) "When I say a naughty word". A longitudinal study of young children's accounts of anger and sadness in themselves and close others. *British Journal of Developmental Psychology* 20, 515-35.
- HURNY, C. (2000) Communicating about cancer: patients' needs and caregivers' skills. *Supportive Care in Cancer*, 8, 437-8.

- HURNY, C. (2002) Do patients with advanced cancer get appropriate information? *Supportive Care in Cancer*, 10, 383-4.
- IMPERATO, J. P., PALEOLOGOS, N. A. & VICK, N. A. (1990) Effects of treatment on long-term survivors with malignant astrocytomas. *Annals of Neurology*, 28, 818-22.
- JACOBSEN, P. B., DONOVAN, K. A. & TRASK, P. C. E. A. (2005) Screening for psychologic distress in ambulatory cancer patients. *Cancer*, 103, 1494-502.
- JANDA, M., EAKIN, E. G., BAILEY, L., WALKER, D. & TROY, K. (2006) Supportive care needs of people with brain tumours and their carers. *Supportive Care in Cancer*, 14, 1094-103.
- JANDA, M., STEGINGA, S., DUNN, J., LANGBECKER, D., WALKER, D. & EAKIN, E. (2008) Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Education and Counselling*, 71, 251-8.
- JANDA, M., STEGINGA, S., LANGBECKER, D., DUNN, J., WALKER, D. & EAKIN, E. (2007) Quality of life among patients with a brain tumor and their carers. *Journal of Psychosomatic Research*, 63, 617-23.
- JANOFF-BULMAN, R. (1992) *Shattered assumptions: towards a new psychology of trauma*, New York, The Free Press.
- JENKINS, V., FALLOWFIELD, L. & SAUL, J. (2001) Information needs of patients with cancer: results from a large study in UK cancer centres. *British Journal of Cancer*, 84, 48-51.
- JONES, R. B., PEARSON, J., CAWSEY, A. J., BENTAL, D., BARRETT, A., WHITE, J., WHITE, C. A. & GILMOUR, W. H. (2006) Effect of different forms of information produced for cancer patients on their use of information, social support and anxiety: a randomised trial. *BMJ*, 332, 942-8.
- JUNCK, L. (2004) Supportive management in neuro-oncology: opportunities for patient care, teaching and research. *Current Opinion in Neurology*, 17, 649-53.
- KAPLAN, C. P. & MINER, M. E. (2000) Relationships: importance for patients with cerebral tumours. *Brain Injury*, 14, 251-9.
- KEARNEY, N., WORTH, A., PATERSON, G. & KENDALL, M. (2003) Patient Experiences of Cancer Care in Scotland: a review of patient experience and involvement in cancer care. Scottish Cancer Group – Quality Improvement Sub-Group.
- KEIR, S. T., CALHOUN-EAGAN, R. D., SWARTZ, J. J., SALEH, O. A. & FRIEDMAN, H. S. (2008a) Screening for distress in patients with brain cancer using the NCCN's rapid screening measure. *Psychooncology*, 17, 621-5.
- KEIR, S. T., FARLAND, M. M., LIPPS, E. S. & FRIEDMAN, H. S. (2008b) Distress persists in long-term brain tumor survivors with glioblastoma multiforme. *Journal of Cancer Survivorship: research and practice*, 2, 269-74.
- KELLY, B., MCCLEMENT, S. & CHOCHINOV, H. M. (2006) Measurement of Psychological Distress in Palliative Care. *Palliative Medicine*, 20, 779-89.

- KEMPER, R. & ROYCE, A. P. (2002) *Chronicling cultures: Long-term field research in anthropology*, Walnut Creek, CA, AltaMira.
- KENDALL, M. (1999) New Spaces, new relationships? Users in the health and social services. PhD Thesis, University of Durham.
- KENDALL, M., BOYD, K., CAMPBELL, C., CORMIE, P., FIFE, S., THOMAS, K., WELLER, D. & MURRAY, S. A. (2006) How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers. *Family practice*, 23, 644-50.
- KENDALL, M., HARRIS, F., BOYD, K., SHEIKH, A., MURRAY, S. A., BROWN, D., MALLINSON, I., KEARNEY, N. & WORTH, A. (2007) Key challenges and ways forward in researching the "good death": qualitative in-depth interview and focus group study. *BMJ*, 334, 521-7.
- KENDALL, M. & MURRAY, S. A. (2005) Tales of the Unexpected: Patients' Poetic Accounts of the Journey to a Diagnosis of Lung Cancer: A Prospective Serial Qualitative Interview Study. *Qualitative Inquiry*, 11, 733-753.
- KENDALL, M., MURRAY, S. A., CARDUFF, E., WORTH, A., HARRIS, F., LLOYD, A., CAVERS, D., GRANT, E., BOYD, K. & SHEIKH, A. (2009) Multi-perspective qualitative interviews: a method to gain an integrated understanding of patients' and carers' beliefs, experiences and needs *BMJ*, 339, b4122.
- KHALILI, Y. (2007) Ongoing transitions: the impact of a malignant brain tumour on patient and family. *AXON*, 28, 5-13.
- KINNERSLEY, P., EDWARDS, A., HOOD, K., RYAN, R., PROUT, H., CADBURY, N., MACBETH, F., BUTOW, P. & BUTLER, C. (2008) Interventions before consultations to help patients address their information needs by encouraging question asking: systematic review. *BMJ*, 337, a485.
- KLEINMAN, A. J. (1988) *The Illness Narratives: suffering, healing and the human condition*, USA, Basic Books Inc.
- KOBASA, S. (1979) Stressful life events, personality and health: an introduction to hardiness. *Journal of Personal and Social Psychology*, 37, 1-11.
- KREX, D., KLINK, B., HARTMANN, C., VON DEIMLING, A., PIETSCH, T., SIMON, M., SABEL, M., STEINBACH, J. P., HEESE, O., REIFENBERGER, G., WELLER, M. & SCHACKERT, G. (2007) Long-term survival with glioblastoma multiforme. *Brain*, 130, 2596-606.
- KRISTJANSON, L. K., MCPHEE, I., PICKSTOCK, S., WILSON, D., OLDHAM, L. & MARTIN, K. (2001) Palliative care nurses' perceptions of good and bad deaths and care expectations: a qualitative analysis. *International Journal of Palliative Nursing*, 7, 129-39.
- KUBLER-ROSS, E. (1989) *On Death and Dying*, London and New York, Routledge.
- LAWTON, J. (2001) Gaining and maintaining consent: ethical concerns raised in a study of dying patients. *Qualitative Health Research*, 11, 693-705.

- LAWTON, J., PEEL, E., PARRY, O. & DOUGLAS, M. (2008) Shifting accountability: A longitudinal qualitative study of diabetes causation accounts. *Social Science and Medicine*, 67, 47-56.
- LAZARUS, R. S. & FOLKMAN, S. (1984) *Stress, appraisal and coping*, New York, Springer Publishing Company, Inc.
- LEAVITT, M. B., LAMB, S. A. & VOSS, B. S. (1996) Brain tumour support group: content themes and mechanisms of support. *Oncology Nursing Forum*, 23, 1247-56.
- LEE, S. & KRISTJANSON, L. (2003) Human research ethics committees: issues in palliative care research. *International Journal of Palliative Nursing*, 9, 13-19.
- LEPOLA, I., TOLJAMO, M., AHO, R. & LOUET, T. (2001) Being a brain tumour patient: a descriptive study of patients' experiences. *Journal of Neuroscience Nursing*, 33, 143-7.
- LEVENTHAL, H., BENYAMINI, Y. & BROWNLEE, S. E. A. (1997) Illness representations: theoretical foundations. IN PETRIE, K. J. & WEINMAN, J. A. (Eds.) *Perceptions of Health and Illness*. Amsterdam, Harwood.
- LEYDON, G. M. (2008) 'Yours is potentially serious but most of these are cured': optimistic consultations in UK outpatient oncology consultations. *Psycho-oncology*, 17, 1081-9.
- LEYDON, G. M., BYNOE-SUTHERLAND, J. & COLEMAN, M. P. (2003) The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers. *European Journal of Cancer Care*, 12, 317-26.
- LIDSTONE, V., BUTTERS, E. & SPEED, P. T. E. A. (2003) Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. *Palliative Medicine*, 17, 588-95.
- LINGARD, L., ALBERT, M. & LEVINSON, W. (2008) Grounded theory, mixed methods and action research. *BMJ*, 337, 459-61.
- LITOFISKY, N. S., FARACE, E., ANDERSON, F., MEYERS, C., HUANG, W. & LAWS, E. R. (2004) Depression in patients with high-grade glioma: results of the glioma outcomes project. *Neurosurgery*, 54, 358-67.
- LITTLE, M., JORDENS, C., PAUL, K. & PHILLIPSON, B. (1998) Liminality: a major category of experience of cancer illness. *Social Science and Medicine*, 47, 1485-94.
- LOHNE, V. (2008) The battle between hoping and suffering: a conceptual model of hope within a context of spinal cord injury. *Advanced Nursing Science*, 31, 237-48.
- LOVELY, M. P. (1996) Changes in cognitive status, mood state, quality of life, functional status, and tumour area in patients with glioblastoma multiforme between time of diagnosis and after radiation therapy. PhD Thesis.
- LOVELY, M. P., MIASKOWSKI, C. & DODD, M. (1999) Relationship between fatigue and quality of life in patients with glioblastoma multiforme. *Oncology Nursing Forum*, 26, 921-5.

- LYONS, G. J. (1996) The 'PRESTON Profile' – the first disease-specific tool for assessing quality of life in patients with malignant glioma. *Disability and Rehabilitation*, 18, 460-8.
- MAGER, W. M. & ANDRYKOWSKI, M. A. (2002) Communication in the cancer 'bad news' consultation: patient perceptions and psychological adjustment. *Psychooncology*, 11, 35-46.
- MAGUIRE, P. (1999) Improving communication with cancer patients *European Journal of Cancer*, 35, 2058-65.
- MAINIO, A., HAKKO, H., NIEMELA, A., KOIVUKANGAS, J. & RASANEN, P. (2005a) Depression and functional outcome in patients with brain tumours: a population based 1-year follow-up study. *Journal of Neurosurgery*, 103, 841-7.
- MAINIO, A., HAKKO, H., NIEMELA, A., KOIVUKANGAS, J. & RASANEN, P. (2006a) Gender differences in relation to depression and quality of life among patients with a primary brain tumour. *European Psychiatry*, 21, 194-9.
- MAINIO, A., HAKKO, H., TIMONEN, M., NIEMELA, A., KOIVUKANGAS, J. & RASANEN, P. (2005b) Depression in relation to survival among neurosurgical patients with a primary brain tumour: a five-year follow-up study. *Neurosurgery*, 56, 1234-42.
- MAINIO, A., TUUNANEN, S., HAKKO, H., NIEMELA, A., KOIVUKANGAS, J. & RASANEN, P. (2006b) Decreased quality of life and depression as predictors for shorter survival among patients with low-grade gliomas: a follow-up from 1990-2003. *European Archives of Clinical Neuroscience*, 256, 516-21.
- MCKENZIE, M. J., CARLSON, L. E., MUNOZ, M. & SPECA, M. (2007) A qualitative study of self-perceived mindfulness-based stress reduction (MBSR) in a psychosocial oncology setting *Stress and Health*, 23, 59-69.
- MCKINNEY, P. A. (2004) Brain Tumours: Incidence, survival and aetiology. *Journal of Neurology, Neurosurgery and Psychiatry*, 75, ii12-ii17.
- MCNAMARA, S. (2007) An Introduction to the role of the neuro-oncology nurse. *Mims Advances*, 4, 2-5.
- MCNAMARA, S. (2008) An overview of palliative care for patients with brain tumours: an interprofessional approach. *British Journal of Neuroscience Nursing*, 4, 435-7.
- MEREDITH, C., SYMONDS, P., WEBSTER, L., LAMONT, D., PYPER, E., GILLIS, C. & FALLOWFIELD, L. (1996) Information needs of cancer patients in West Scotland: cross-sectional survey of patients' views. *BMJ*, 313, 724-6.
- MILBERG, A., OLSSON, E. C., JAKOBSSON, M., OLSSON, M. & FRIEDRICHSEN, M. (2008) Family members' perceived needs for bereavement follow-up. *Journal of Pain and Symptom Management*, 35, 58-69.
- MILES, M. B. & HUBERMAN, A. M. (1994) *Qualitative Data Analysis: an expanded sourcebook*, Thousand Oaks, CA; London, Sage.

- MILLER, S. M. (1987) Monitoring and blunting: validation of a questionnaire to assess styles of information seeking under threat. *Journal of Personality and Social Psychology*, 52, 345-53.
- MINNITI, G., DE SANCTIS, V., MUNI, R., FILIPPONE, F., BOZZAO, A., VALERIANI, M., OSTI, M. F., DE PAULA, U., LANZETTA, G., TOMBOLINI, V. & ENRICI, R. M. (2008) Radiotherapy plus concomitant and adjuvant temozolomide for glioblastoma in elderly patients. *Journal of Neuro-oncology*, 88, 97-103
- MORRIS, S. M. (2001) Joint and individual interviewing in the context of cancer. *Qualitative Health Research* 11, 553-7.
- MURRAY, M. & CHAMBERLAIN, K. (Eds.) (1999) *Qualitative Health Psychology: theories and methods*, London, Sage.
- MURRAY, S., BARCLAY, S., BENNETT, M. I., KENDALL, M., AMIR, Z. & LLOYD-WILLIAMS, M. (2008) Palliative care research in the community: it is time to progress this emerging field. *Palliative Medicine*, 22, 609-11.
- MURRAY, S. A., BOYD, K., KENDALL, M., WORTH, A., BENTON, T. F. & CLAUSEN, H. (2002) Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ*, 325, 929-32.
- MURRAY, S. A., KENDALL, M., BOYD, K., WORTH, A. & BENTON, T. F. (2003) General practitioners and their possible role in providing spiritual care: a qualitative study. *British Journal of General Practice*, 53, 957-9.
- MURRAY, S. A., KENDALL, M., BOYD, K., WORTH, A. & BENTON, T. F. (2004) Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliative Medicine*, 18, 39-45.
- MURRAY, S. A., KENDALL, M., CARDUFF, E., WORTH, A., HARRIS, F., LLOYD, A., CAVERS, D., GRANT, E. & SHEIKH, A. (2009) Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ*, 339, b3702.
- MURRAY, S. A., KENDALL, M., GRANT, E., BOYD, K., BARCLAY, S. & SHEIKH, A. (2007) Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. *Journal of Pain and Symptom Management*, 34, 393-402.
- MURRAY, S. A., MITCHELL, G. K., BURGE, F., BARNARD, A., NOWELS, D. & CHARLTON, R. (2006) It's time to develop primary care services for the dying. *Journal of Palliative Care*, 22, 115-6.
- MURRAY, S. A. & SHEIKH, A. (2006) Serial interviews for patients with progressive diseases. *Lancet*, 368, 901-2.
- NEALE, B. (2008) Researching personal lives and relationships through the lens of time: conceptual and practical dimensions. *Understanding families and relationships over time*. Conference Presentation, Dynamic Earth, Edinburgh.

- NEKOLAICHUK, C. L., JEVNE, R. F. & MAGUIRE, T. O. (1999) Structuring the meaning of hope in health and illness *Social Science and Medicine*, 48, 591-605.
- NHS EDUCATION FOR SCOTLAND (2009) Spiritual Care Matters: an Introductory Resource for all NHS Scotland Staff, NHS Education for Scotland.
- NICE (2006b) Improving outcomes in brain and other central nervous system tumours – draft guidance. <http://www.nice.org.uk/page.aspx?o=261073> accessed 10.11.08
- NICE (2007) Glioma (newly diagnosed and high grade) - carmustine implants and temozolomide: guidance. <http://www.nice.org.uk/nicemedia/pdf/TA121guidance.pdf> accessed 5.11.08
- O'BAUGH, J., WILKES, L. M., LUKE, S. & GEORGE, A. (2003) 'Being positive': perceptions of patients with cancer and their nurses. *Journal of Advanced Nursing*, 44, 262-70.
- O'CONNOR, A. M., STACEY, D., ENTWHISTLE, V., LLEWELLYN-THOMAS, H., ROVNER, D., HOLMES-ROVNER, M., TAIT, V., TETROE, J., Fiset, V., BARRY, M. & JONES, D. (2008) Decision aids for people facing health treatment or screening decisions (Review). The Cochrane Collaboration, Wiley.
- PARKER, P. A., BAILE, W. F., DE MOOR, C., LENZI, R., KUDELKA, A. P. & COHEN, L. (2001) Breaking bad news about cancer: patients' preferences for communication. *Journal of Clinical Oncology*, 19, 2049-56.
- PARKES, C. M. (1971) Psycho-social transitions: a field for study. *Social Science and Medicine*, 5, 101-15.
- PARSONS, T. (1951) *The Social System*, New York, Free Press.
- PELLETIER, G., VERHOEF, M. J., KHATRI, N. & HAGEN, N. (2002) Quality of life in brain tumor patients: the relative contributions of depression, fatigue, emotional distress, and existential issues. *Journal of Neuro-oncology*, 57, 41-9.
- PERKINS, P., BARCLAY, S. & BOOTH, S. (2007) What are patients' priorities for palliative care research? Focus group study. *Palliative Medicine*, 21, 219-26.
- PIGGOT, C., POLLARD, A., THOMSON, K. & ARANDA, S. (2009) Unmet needs in cancer patients: development of a supportive needs screening tool (SNST). *Supportive Care in Cancer*, 17, 33-45.
- POLARD, A. & FILER, A. (2000) *The Social World of Pupil Assessment: Processes and Contexts of Primary Education*, London, Continuum.
- POLLOCK, K., COX, K., HOWARD, P., WILSON, E. & MOGHADDAM, N. (2008) Service user experiences of information delivery after a diagnosis of cancer: a qualitative study. *Supportive Care in Cancer*, 16, 963-73.
- POPE, C. & MAYS, N. (2009) Critical reflections on the rise of qualitative research. *BMJ*, 339, 737-9.
- POTTER, J., HAMI, F., BRYAN, T. & QUIGLEY, C. (2003) Symptoms in 400 patients referred to palliative care services: prevalence and patterns. *Palliative Medicine*, 17, 310-314.

- POTTER, J. & WHETHERALL, M. (1987) *Discourse and social psychology: beyond attitudes and behaviour*, London, Sage.
- PRATT, R. (2002) Nobody's ever asked how I felt. IN WILKINSON, H. (Ed.) *The Perspectives of People with Dementia: Research methods and motivations*. London, Jessica Kingsley Publishers.
- PRINGLE, A. M., TAYLOR, R. & WHITTLE, I. R. (1999) Anxiety and depression in patients with an intracranial neoplasm before and after tumour surgery. *British Journal of Neurosurgery*, 13, 46-51.
- QSR INTERNATIONAL (2006) NVivo www.qsrinternational.com
- RABIN, C., ROGERS, M., PINTO, B. M., NASH, J. M., FRIERSON, G. M. & TRASK, P. C. (2007) Effect of personal cancer history and family cancer history on levels of psychological distress. *Social Science and Medicine*, 64, 411-6.
- RAMPLING, R. L., JAMES, A. & PAPANASTASSIOU, V. (2004) The present and future management of malignant brain tumours: surgery, radiotherapy, chemotherapy. *Journal of Neurology, Neurosurgery, Psychiatry*, 75, ii24-ii30.
- REEVES, S., KUPER, A. & HODGES, B. D. (2008) Qualitative research methodologies: ethnography. *BMJ*, 337, 512-4.
- REISSMAN, C. K. (1993) *Narrative Analysis*, London, Sage.
- RICHIE, J. & SPENCER, L. (1994) Qualitative data analysis for applied policy research. IN BRYMAN, A. & BURGESS, R. G. E. (Eds.) *Analysing Qualitative Data*. London, Sage.
- RIER, D. A. (2000) The missing voice of the critically ill: a medical sociologist's first-person account *Sociology of Health and Illness*, 22, 68-93.
- RIJMEN, F., IP, E. H., RAPP, S. & SHAW, E. G. (2008) Qualitative longitudinal analysis of symptoms in patients with primary and metastatic brain tumours. *Journal of the Royal Statistical Society Series - Statistics in Society*, 171, 739-53.
- RILEY, J. & ROSS, J. R. (2005) Research into care at the end of life. *Lancet*, 385, 735-7.
- ROGERS, S. N., EL-SHEIKHA, J. & LOWE, D. (2009) The development of a Patients Concerns Inventory (PCI) to help raise patients' concerns in the head and neck clinic. *Oral Oncology*, 45, 555-61.
- ROSE, K. E. (1999) A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing*, 8, 81-8.
- ROTH, A. J., KORNBLITH, A. B., BATEL-COPEL, L., PEABODY, E., SCHER, H. I. & HOLLAND, J. C. (1998) Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer*, 82, 10, 1904-8.
- ROTTER, J. B. (1966) Generalised expectancies for internal versus external control of reinforcement. *Psychological Monogram*, 80, 1-26.
- ROWLANDS, J. & NOBLE, S. (2008) How does the environment impact on the quality of life of advanced cancer patients? A qualitative study with implications for ward design. *Palliative Medicine*, 22, 768-74.

- RUTTER, M. (1985) Resilience in the face of adversity. *British Journal of Psychiatry*, 147, 598-611.
- RYAN, H., SCHOFIELD, P., COCKBURN, J., BUTOW, P., TATTERSAL, M. H. N., TURNER, J., GIRGIS, A., BANDARANAYAKE, D. & BOWMAN, D. (2005) How to recognise and manage psychological distress in cancer patients. *European Journal of Cancer Care*, 14, 7-15.
- SACHS, G. A. (1998) Informed Consent for Research on Human Subjects with Dementia AGS Ethics Committee. *Position paper*. American Geriatrics Society.
- SALANDER, P. (1996) Brain tumours as a threat to life and personality: the spouses perspective. *Journal of Psychosocial oncology*, 14, 1-18.
- SALANDER, P. (2000) Using beliefs and magical thinking to fight cancer distress-a case study. *Psychooncology*, 9, 40-3.
- SALANDER, P. (2002) Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients. *Social Science and Medicine*, 55, 721-32.
- SALANDER, P. (2006) Who needs the concept of 'spirituality'? *Psychooncology*, 15, 647-9.
- SALANDER, P., BERGENHEIM, A. T., HAMBERG, K. & HENRIKSSON, R. (1999) Pathways from symptoms to medical care: a descriptive study of symptom development and obstacles to early diagnosis in brain tumour patients. *Family Practice*, 16, 143-8.
- SALANDER, P., BERGENHEIM, A. T. & HENRIKSSON, R. (2000) How was life after treatment of a malignant brain tumour? *Social Science and Medicine*, 51, 589-98.
- SALANDER, P., BERGENHEIM, T. & HENRIKSSON, R. (1996) The creation of protection and hope in patients with malignant brain tumours. *Social Science and Medicine*, 42, 985-96.
- SALANDER, P., KARLSSON, T. & BERGENHEIM, A. T. (1998) Comment on Weitzner and Meyers. *Psychooncology*, 7, 141-5.
- SALANDER, P. & SPETZ, A. (2002) How do patients and spouses deal with the serious facts of malignant glioma? *Palliative Medicine*, 16, 305-13.
- SALANDER, P. & WINDAHL, G. (1999) Does 'denial' really cover our everyday experiences in clinical oncology? A critical view from a psychoanalytic perspective on the use of 'denial'. *British Journal of Medical Psychology*, 72 267-79.
- SALDANA, J. (2003) *Longitudinal Qualitative Research: Analyzing Change Through Time*, Walnut Creek, CA: AltaMira Press.
- SALMON, P. & HALL, G. M. (2003) Patient empowerment and control: a psychological discourse in the service of medicine. *Social Science and Medicine*, 57, 1969-80.
- SALMON, P. & HALL, G. M. (2004) Patient empowerment or the emperor's new clothes. *Journal of the Royal Society of Medicine*, 97, 53-6.
- SALO, J., NIEMELA, A., JOUKAMAA, M. & KOIVUKANGAS, J. (2002) Effect of brain tumour laterality on patients' perceived quality of life. *Journal of Neurology, Neurosurgery and Psychiatry*, 72, 373-7.

- SAND, L., OLSSON, M. & STRANG, P. (2009) Coping Strategies in the Presence of One's Own Impending Death from Cancer. *Journal of Pain and Symptom Management*, 37, 13-22.
- SANSON-FISHER, R., GIRGIS, A., BOYES, A., BONEVSKI, B., BURTON, L. & COOK, P. (2000) The unmet supportive care needs of patients with cancer. *Cancer*, 88, 226-37.
- SARDELL, S., SHARPE, G., ASHLEY, D., GUERRERO, D. & BRADA, M. (2000) Evaluation of a nurse-led telephone clinic in the follow-up of patients with malignant glioma. *Clinical Oncology*, 12, 36-41.
- SAUNDERS, C. M. (1981) The founding philosophy. IN SAUNDERS, C. M., SUMMERS, D. H. & TELLER, N. (Eds.) *Hospice: the living idea*. London, Edward Arnold.
- SCHEIER, M. F. & CARVER, C. S. (2001) Adapting to Cancer: the importance of hope and purpose. IN BAUM, E. & ANDERSEN, B. L. (Eds.) *Psychosocial Interventions for Cancer*. Washington, DC, American Psychological Association.
- SCHMIDINGER, M., LINZMAER, L., BECHERER, A., FAZENY-DOERNER, B., FAKHRAI, N., PRAYER, D., KILLER, M., UNGERSBOECK, K., DIECKMANN, K. & MAROSI, C. (2003) Psychometric and quality of life assessment in long-term glioblastoma survivors *Journal of Neuro-oncology*, 63, 55-61.
- SCOTTISH EXECUTIVE (2004) Cancer in Scotland: Sustaining Change: Cancer Incidence Projections for Scotland.
<http://www.scotland.gov.uk/Publications/2004/12/20257/46699> accessed 25.10.08
- SCOTTISH EXECUTIVE (September 2008) Living and Dying Well: a national action plan for palliative and end of life care in Scotland. Scottish Executive.
- SCHUBART, J. R., KINZIE, M. B. & FARACE, E. (2008) Caring for the brain tumor patient: Family caregiver burden and unmet needs *Neuro-oncology*, 10, 61-72.
- SEALE, C. (1999a) Generalising from Qualitative Research *The Quality of Qualitative Research*, London, Sage.
- SEALE, C. (1999b) Trust, Truth and Philosophy. *The Quality of Qualitative Research*. Sage.
- SELIGMAN, M. E. P. (1991) *Learned optimism*, New York, Knopf.
- SEPUCHA, K., BELKORA, J., TRIPATHY, D. & ESSERMAN, L. (2000) Building Bridges between physicians and patients: Results of a pilot study examining new tools for collaborative decision making in breast cancer. *Journal of Clinical Oncology*, 18, 1230-8.
- SEYMOUR, J., PAYNE, S., REID, D., SARGEANT, A., SKILBECK, J. & SMITH, P. (2005) Ethical and methodological issues in palliative care studies: the experiences of a research group. *Journal of Research in Nursing*, 10, 169-88.
- SHERWOOD, P. (2004) Family care of persons living with a brain tumour.
- SHERWOOD, P., GIVEN, B. A., DOORENBOS, A. Z. & GIVEN, C. (2004a) Forgotten voices: lessons from bereaved caregivers of persons with a brain tumour. *International Journal of Palliative Nursing*, 10, 67-75.

- SHERWOOD, P., GIVEN, B. A., GIVEN, C., SCHIFFMAN, R., MURMAN, D. L. & LOVELY, M. (2004b) Caregivers of persons with a brain tumor: a conceptual model. *Nursing Inquiry*, 11, 43-53.
- SHERWOOD, P. R., GIVEN, B. A., GIVEN, C. W., SCHIFFMAN, R. F., MURMAN, D. L. & LOVELY, M. E. A. (2006) Predictors of distress in caregivers of a primary malignant brain tumor. *Research in Nursing and Health*, 29, 105-20.
- SHIPMAN, C., GYSELS, M., WHITE, P., WORTH, A., MURRAY, S. A., BARCLAY, S., FORREST, S., SHEPHERD, J., DALE, J. & DEWAR, S. (2008a) Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. *BMJ*, 337, 848-51.
- SHIPMAN, C., HOTOPF, M., RICHARDSON, A., MURRAY, M., KOFFMAN, J., HARDING, R., SPECK, P. & HIGGINSON, I. J. (2008b) The views of patients with advanced cancer regarding participation in serial questionnaire studies. *Palliative Medicine*, 22, 913-20.
- SIJBEN, A. E., MCINTYRE, J. B., ROLDÁN, G. B., EASAW, J. C., YAN, E., FORSYTH, P. A., PARNEY, I. F., MAGLIOCCO, A. M., BERNSEN, H. & CAIRNCROSS, J. G. (2008) Toxicity from chemoradiotherapy in older patients with glioblastoma multiforme. *Neuro-oncology*, 89, 97-103.
- SILVERMAN, D. (1993) *Interpreting Qualitative Data: Methods for analysing talk, text and interaction*, London, Sage.
- SMITH, J. A., HARRE, R. & VAN LANGENHOVE, L. (1995) Introduction. IN SMITH, J. A., HARRE, R. & VAN LANGENHOVE, L. (Eds.) *Rethinking Health Psychology*, London, Sage.
- SOOTHILL, K., MORRIS, S. M., HARMAN, J., FRANCIS, B., THOMAS, C. & MCILLMURRAY, M. B. (2001a) The significant unmet needs of cancer patients: probing psychosocial concerns. *Supportive Care in Cancer*, 9, 597-605.
- SOOTHILL, K., MORRIS, S. M., HARMAN, J. C., FRANCIS, B., THOMAS, C. & MCILLMURRAY, M. B. (2001b) Informal carers of cancer patients: what are their unmet psychosocial needs? *Health and Social Care in the Community*, 9, 464-75.
- SPETZ, A., HENRIKSSON, R., BERGENHEIM, A. T. & SALANDER, P. (2005) A specialist nurse-function in neurooncology: a qualitative study of possibilities, limitations, and pitfalls. *Palliative and Supportive Care*, 3, 121-30.
- STEINHAUSER, K. E., CLIPP, E. C., HAYS, J. C., OLSEN, M., ARNOLD, R., CHRISTAKIS, N. A., LINDQUIST, J. H. & TULSKY, J. A. (2006a) Identifying, recruiting and retaining seriously ill patients and their caregivers in longitudinal research. *Palliative Medicine*, 20, 745-54.
- STEINHAUSER, K. E., VOILS, C. I., CLIPP, E. C. & AL, E. (2006b) 'Are you at peace?': one item to probe spiritual concerns at the end of life. *Archives of Internal Medicine*, 166, 101-5.

- STRANG, S. & STRANG, P. (2001) Spiritual thoughts, coping and sense of 'coherence' in brain tumour patients and their spouses. *Palliative Medicine*, 15, 127-34.
- STRANG, S., STRANG, P. & TERNESTEDT, B.-M. (2001) Existential support in brain tumour patients and their spouses. *Supportive Care in Cancer*, 9, 625-33.
- STRAUSS, A. & CORBIN, J. (1998) *Basics of Qualitative Research: Grounded theory procedures and techniques*, Thousand Oaks, CA, SAGE.
- STRONG, V., WATERS, R., HIBBERD, C., MURRAY, G., WALL, L., WALKER, J., MCHUGH, G., WALKER, A. & SHARPE, M. (2008) Management of depression for people with cancer (SMaRT oncology 1): a randomised trial. *Lancet*, 372, 40-8.
- STUPP, R., MASON, W. P., VAN DEN BENT, M. J., WELLER, M., FISHER, B., TAPHOORN, M. J. B. E. A. & European Organisation for Research and Treatment of Cancer Brain Tumor and Radiotherapy Groups; National Cancer Institute of Canada Clinical Trials Group (2005) Radiotherapy plus concomitant and adjuvant temozolomide for glioblastoma *New England Journal of Medicine*, 352, 987-96.
- SWALLOW, V., LAMBERT, H., CLARKE, C., CAMPBELL, S. & JACOBY, A. (2008) Childhood chronic-kidney-disease: A longitudinal-qualitative study of families learning to share management early in the trajectory. *Patient Education and Counselling*, 73, 354-62.
- TAILLIBERT, S., LAIGLE-DONADEY, F. & SANSON, M. (2004) Palliative care in patients with primary brain tumours. *Current Opinion in Oncology*, 16, 587-92.
- TAPHOORN, M. J., HEIMANS, J. J., SNOEK, F. J., LINDEBOOM, J., OOSTERINK, B., WOLBERS, J. G. & KARIM, A. B. (1992) Assessment of quality of life in patients treated for low-grade glioma: a preliminary report. *Journal of Neurology, Neurosurgery and Psychiatry*, 55, 372-6.
- TAPHOORN, M. J. B., SCHIPHORST, A. K., SNOEK, F. J., LINDEBOOM, J., WOLBERS, J. G., KARIM, A. B. M. F., HUIJGENS, P. C. & HEIMANS, J. J. (1994) Cognitive functions and quality of life in patients with low-grade gliomas: The impact of radiotherapy. *Annals of Neurology*, 36, 49-55.
- TAYLOR, B., GLASS, N., MCFARLANE, J. & STIRLING, K. (2001) Views of nurses, patients and patients' families regarding palliative nursing care. *International Journal of Palliative Nursing*, 7, 186-91.
- TAYLOR, S. E. (1983) Adjustment to threatening events. A theory of cognitive adaptation. *American Psychologist*, 38, 1161-73.
- THOMSON, R. & HOLLAND, J. (2003) Hindsight, foresight and insight: the challenges of qualitative longitudinal qualitative research. *International Journal of Social Research Methodology*, 6, 233-44.
- THOMSON, R., PLUMRIDGE, L. & HOLLAND, J. (2003) Longitudinal qualitative research: a developing methodology. *International Journal of Social Research Methodology*, 6, 185-7.

- USSHER, J., KIRSTEN, L., BUTOW, P. & SANDOVAL, M. (2006) What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science and Medicine*, 62, 2565-76.
- VIVAT, B. (2006) The whole and the parts: spiritual care in a West of Scotland hospice. PhD Thesis, University of Edinburgh.
- VOOGT, E., VAN LEEUWEN, A. F., VISSER, A. P., VAN DER HEIDE, A. & VAN DER MAAS, P. J. (2005) Information needs of patients with incurable cancer. *Supportive Care in Cancer*, 13, 943-8.
- WALLACE, P. (2001) Improving palliative care through effective communication. *International Journal of Palliative Nursing*, 7, 86-90.
- WATSON, M., GREER, S., ROWDEN, L., GORMAN, C., ROBERTSON, B., BLISS, J. & TUNMORE, R. (1991) Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. *Psychological Medicine*, 21, 51-7.
- WEISMAN, A. D. & WORDEN, J. W. (1997) The existential plight in cancer: the significance of the first 100 days. *International Journal of Psychological Medicine*, 7, 1-15.
- WEITZNER, M. A. & MEYERS, C. A. (1997) Cognitive functioning and quality of life in malignant glioma patients: a review of the literature. *Psychooncology*, 6, 169-77.
- WEITZNER, M. A., MEYERS, C. A. & BYRNE, K. (1996) Psychosocial functioning and quality of life in patients with primary brain tumors. *Journal of Neurosurgery*, 84, 29-34.
- WELLISCH, D. K., KALEITA, T. A., FREEMAN, D., CLOUGHESY, T. & GOLDMAN, J. (2002) Predicting major depression in brain tumour patients. *Psychooncology*, 11, 230-8.
- WENGER, G. C. (1999) Advantages gained by combining qualitative and quantitative data in longitudinal study. *Journal of Ageing Studies*, 13, 369-76.
- WHITE, C.A., WOODFIELD, C., RITCHIE, J. Reporting and Presenting Qualitative Research. In RITCHIE, J. & LEWIS, J. (Eds) *Qualitative Research Practice: a guide for social science students and researchers*, London, Thousand Oaks, New Delhi: SAGE, 2003: 287-320.
- WIDEHEIM, A. K., EDVARDSSON, T., PAHLSON, A. & AHLSTROM, G. (2002) A family's perspective on living with a highly malignant brain tumor. *Cancer Nursing*, 25, 236-44.
- WILES, R., COTT, C. & GIBSON, B. E. (2008) Hope, expectation and recovery from illness: a narrative synthesis of qualitative research. *Journal of Advanced Nursing*, 64, 564-73.
- WILLARD, C. & LUKER, K. (2005) Supportive care in the cancer setting: rhetoric or reality? *Palliative Medicine*, 19, 328-33.

- WONG, R. K. S., FRANSSEN, E., SZUMACHER, E., CONNOLLY, R., EVANS, M. & PAGE, B. (2002) What do patients living with advanced cancer and their carers want to know? - a needs assessment. *Supportive Care in Cancer*, 10, 408-15.
- WORLD HEALTH ORGANISATION (2002) WHO definition of palliative care. <http://www.who.int/cancer/palliative/definition/en/> accessed 08.12.2008
- WORLD HEALTH ORGANISATION (2007) WHO Classification of the Central Nervous System. 4th edition ed., WHO
- WORTH, A., BOYD, K., KENDALL, M., HEANEY, D., MACLEOD, U., CORMIE, P., HOCKLEY, J. & MURRAY, S. (2006) Out-of-hours palliative care: a qualitative study of cancer patients, carers and professionals. *British Journal of General Practice*, 56, 6-13.
- WORTH, A., IRSHAD, T., BHOPAL, R., BROWN, D., LAWTON, J., GRANT, E., MURRAY, S.A., KENDALL, M., ADAM, J., GARDEE, R. & SHEIKH, A. (2009) Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *BMJ*, 338, b183.
- WYNESS, M. A., DURITY, M. B. & DURITY, F. (2002) Narratives of patients with skull base tumours and their family members: lessons for nursing practice. *Axone*, 24, 18-35.
- ZWAHLEN, D., HAGENBUCH, N., CARLEY, M. I., RECKLITIS, C. J. & BUCHI, S. (2008) Screening cancer patients' families with the distress thermometer (DT): a validation study. *Psychooncology*, 17, 959-66.

Appendices

Appendix One: Review methods and results

Due to the exploratory nature of the research questions being addressed by this review, difficulties were encountered in designing the review according to conventional systematic review methodology for such a diverse and complex body of literature consisting of predominantly qualitative research. Variations on review methodology for more diverse literature have been developed and difficulties outlined e.g. (Britten et al., 2002, Dixon-Woods et al., 2004a, Dixon-Woods et al., 2006). For example, it was impossible to specify in advance the categories under which the findings would be summarised in this review. Qualitative literature is notoriously harder to identify when searching literature databases, and the effectiveness and efficiency of searching databases alone is questionable (Greenhalgh and Peacock, 2005). Searching becomes more of an iterative process as new search terms become apparent as key papers arise. Reference chaining of these key papers is also crucial.

This review was not an interpretative review seeking to meta-synthesise findings in order to develop a higher order theory on the topic. Instead, an integrative review of the evidence on living with a glioma was conducted of which a descriptive account will be given here.

Aims of the searching phase

The searching phase of this study aimed:

- to identify papers that explore the lived experience of a brain tumour for patients and their carers/ families
- to identify papers that explore the psychosocial issues associated with living with a brain tumour in particular

- To identify a small number of articles on relevant psychosocial issues in health and illness more broadly

The principal objective of the searching phase was to identify all candidate studies irrespective of their quality eventual inclusion in the review. The initial yield from the search will provide a sampling frame from which relevant studies of sufficient quality will be screened and selected.

Search strategy

Evidence will be searched for using:

- The databases listed in table seven.
- Follow-up of reference lists in a selection of key papers.
- Key academic authors and seminal articles (e.g. Davies, Salander).
- Grey literature (unpublished studies found in Google scholar and digital dissertations.)

Searches of literature databases

The sources listed in table seven were searched systematically using the search terms listed in table eight. However, the format of the databases varied significantly and so searches were adapted to suit individual databases. I did attempt to be exhaustive within the means of each database.

Medline
Embase
PubMed (related articles)
CINAHL
ASSIA
CancerLit
PsychINFO
AMED
SCI
SSCI (Web of Science)
British Nursing Index (BNI)
ZETOC
BIOSIS

Table 7: Literature databases

	OR	OR	OR
AND	Brain tumour terms	Psychosocial terms	Methods terms
	Glioma(s)	Psychological	Qualitative
	Brain tumour	Psychosocial	Longitudinal
	Brain tumor	Psychology	In-depth interviews
	Brain neoplasm(s)	Carer(s)	Interview(s)
	Glioblastoma	Caregiver(s)	Unstructured interview(s)
	Glioblastoma multiforme	Care-giver(s)	Observational study
	Astrocytoma	Family	Ethnograph\$
	Anaplastic astrocytoma	Relatives	Grounded theory
	Oligodendroglioma	Patient care	Constant comparative method
	Brain cancer	Support	Discourse analysis
	Neuro-oncology	Information	Interpretive phenomenological
	Neurooncology	Communication	analysis
		Unmet need(s)	Theoretical
		Lived experience	Thematic analysis

		Life experience	Glaser
		Experience	Strauss
		Depression	Focus group
		Anxiety	Narrative analysis
		Coping	
		Palliative care	
		Palliat\$	
		Satisfaction	
		Quality-of-life	
		Quality of life	
		Follow-up	
		Rehabilitation	
		Supportive care	
		Distress	
		Psychiatric disorder	
		Psychiatric morbidity	
		Spiritual\$	
		Existential	
		Emotional	
		Social	

Table 8: Search terms

Screening

Articles were screened for relevance and methodological quality for inclusion in the review (see Appendix Four for more detail on assessing quality of work). A policy of maximum inclusion was employed.

Relevance

Due to the broad theoretical nature of the study area, an inclusive policy of articles was adopted. I prioritised papers that appeared to be relevant, rather than prioritising studies that met particular methodological standards. This is a technique that prioritises “signal” (relevance) over “noise” (poor methodological quality), as is suggested by Edwards when approaching a review of a diffuse topic area (Edwards et al., 2000).

Articles were screened according to the following criteria:

- *Does the article refer to gliomas or other malignant brain tumours in adults?*
- *Does the article inquire into an aspect of the lived experience of glioma?*
- *Does the article have a link with the review topic that could be of interest?*

Articles deemed not relevant were excluded from the review.

Methodological quality

Assessing methodological quality in such a diverse set of literature was a difficult task. While a standard formula and set of criterion exists for determining quality of quantitative evidence, the debate surrounding the assessment of quality in qualitative research continues. The debate includes arguments over whether it is possible to assess qualitative research in this way at all and if so, what is the best way to do so (Dixon-Woods et al., 2004b). No such hierarchy of evidence exists as it does in systematic reviews of purely quantitative empirical literature where randomised controlled trials are considered more rigorous and robust, providing strict and clear criteria for judging evidence. A more fluid and inclusive approach was adopted here. A low threshold for inclusion was adopted in order to retain a wide variety of concepts addressed in the

literature. Appendix Four shows a broad set of prompts used to evaluate the literature included in this chapter.

Results

A broader search of the cancer literature shows a wealth of papers relating to experience of breast cancer, prostate cancer or paediatric cancers but very little pertaining to adult brain tumours. The number of articles identified in each database using a broader search was in excess of 50 000. In order to identify the relevant articles it was necessary to focus the search using brain tumour search terms only.

Using the search terms detailed in table eight, databases Medline, Embase and CINAHL were searched simultaneously. A combined search of the three sets of search terms yielded 874 records including duplicates (452 Medline, 367 Embase, 56 CINAHL). The vast majority of these were not relevant. Abstracts were screened for relevance and 55 records remained (22 CINAHL, 23 EMBASE and 10 Medline). Articles screened out did not refer to adult brain tumours, non-English language articles, related to treatment developments or tended to refer to cognitive neuropsychological function or risks associated with causing brain tumours. Quality of life articles were retained.

A search of AMED, BNI and PsychINFO yielded 57 results (9 AMED, 1 BNI and 43 PsychINFO) after duplicates were removed. There is mostly overlap/ duplication with the results from other databases. On the whole, the results from these databases are much more relevant than those from Medline and EMBASE. The articles removed from the set were related to paediatric brain tumours or risks associated with causing brain tumours. Of the 57 articles identified, 27 were retained (6 AMED, 1 BNI and 20 PsychINFO).

A search of ASSIA identified 10 articles in all, 5 of which were relevant to this review. However, all of these articles had been identified by other databases.

A search of CancerLit on PubMed yielded 846 articles in total, of which 34 were relevant. The vast majority were not relevant, covering mainly clinical aspects, treatment development and causes of gliomas.

Social Science Citation Index and Science Citation Index identified 382 articles, of which 27 were retained.

Databases such as ZETOC, BIOSIS and Digital Dissertations could not be searched using the full combination of terms. A more fluid searching approach using the key terms was used. ZETOC yielded only one record in this way, which was not relevant to the review. BIOSIS identified 82 records, 9 of which were retained. No new articles were identified.

A simple search of all databases using the terms 'glioma' and 'qualitative' only yielded 105 articles once duplicates were removed of which only 11 articles overlapped with those deemed relevant from the detailed search. Certain search terms were not sufficiently directed and did not target relevant papers. For example, using terms such as 'follow up' and 'IPA' identified many irrelevant articles.

Reference chaining or 'snowballing' was an effective means of finding relevant papers. By searching reference sections of key papers, further articles related to that topic that may not otherwise have been picked up in the database searches could be identified for inclusion in the review. In many cases where searching and identifying qualitative literature is problematic due, for example, to lack of commonly used key words, using reference chaining is an effective proxy.

Appendix Two: Clinical depression and anxiety in brain tumour patients

A short summary of some of the key articles examining depression and anxiety in people with a brain tumour diagnosis are presented below.

Wellisch *et al* have attempted to address the lack of published articles diagnosing major depressive disorder (MDD) using the DSM-IV criteria in their study of 89 brain tumour patients (aged 18-76) (Wellisch et al., 2002). Unusually, brain tumour patients were evaluated for presence of MDD using a structured psychiatric interview in addition to a battery of neuropsychological tests. Interestingly family members were always present during the psychiatric interview and it is therefore possible that the information given/retrieved interviews may be different than if they interviews had been conducted privately. There were significant neuropsychological problems among the participants in this study. 28% of patients were diagnosed with MDD (n=25) while depressive symptoms were attributed to organic brain disease in a further 8% (n=6), stating higher levels compared with other studies of depression in cancer patients, although contrasting evidence has been reported (Pringle et al., 1999). Many of the self-reported symptoms, as Wellisch *et al* point are, were also physical symptoms of brain disease and so it is arguably impossible to assess the root of these symptoms. Having a frontal region tumour, sadness and lack of motivation; and a family psychiatric history were highly significantly predictive of MDD.

Litofsky *et al* have also used the DSM-IV criteria to diagnose depression in patients specifically with high-grade glioma (Litofsky et al., 2004). In their study, Litofsky *et al* have compared physician diagnosis with patient self reports and impact of depression on survival using data from up to 598 high-grade glioma patients (aged 18-87.9 years

median 55 years) over a 6 month period as part of a large scale Glioma Outcomes Project. Litofsky *et al* have signalled the prevalence of depression in patients with glioblastoma, the link between incidence of depression and survival, the discrepancy between patients and physician reports and the lack of treatment of the disorder. The authors have also highlighted to differences in rates of depression in brain tumour patients reported in the literature and suggest that this is in part an artefact of the methods and measures used.

Mainio *et al* in Finland have focussed on the relationship between depression and survival in 75 patients with a primary brain tumour (Mainio et al., 2005b) as part of their broader research into depression, quality of life and outcomes of survival (Mainio et al., 2006b, Mainio et al., 2006a) and functional status (Mainio et al., 2005a). Location of tumour and extent of surgery were both associated with length of survival in patients with a low-grade (particularly those with a history of depression) or benign tumour but not in patients with a high-grade tumour. Depression ranged from 2.5% to 15.4% in the patients studied and varied according to tumour type; extent of resection and treatment given. Overall, results indicated a strong association between current (preoperative) depression and survival in low-grade glioma patients, moreso than in patients in the other groups, supporting Litofsky's findings (Litofsky et al., 2004).

Anderson *et al* have examined anxiety and depression *after* treatment for a brain tumour in 40 patients (24 male, 16 female; aged 16-65) with low-grade, high-grade or benign tumours (Anderson et al., 1999). Only 5% (n=2) of patients had a significant level of anxiety and 15% (n=6) for physician reported depression using the Hamilton Rating Scale for Depression and Clinical Anxiety Scale. Patient reports for anxiety and depression were 11% (n=4) and 0% respectively using the Hospital Anxiety and Depression Scale (HADS). Patients with a high-grade tumour and those with physical and cognitive deficit were found to have higher rates of depression but this was not

statistically significant. This study found particularly low rates of depression in anxiety of brain tumour patients.

D'Angelo *et al* have more recently looked at the period before and after surgery in their study of state and trait anxiety and depression in 114 patients (45 male, 65 female) with a primary brain tumour over a one-year follow-up period (D'Angelo et al., 2008). State and trait anxiety were relatively high before surgery compared with a low incidence of depression at this time. While state and trait anxiety remained stable, depression was found to increase in patients over the one-year follow-up period. As time progressed, State anxiety was correlated with having current depression, an association that endured over time. Women were also more likely to possess state and trait anxiety and current depression. These findings have implications for being able to predict depression in brain tumour patients and target those who are at risk.

Strong *et al* have evaluated an intervention to manage depression in patients with cancer being treated at a Scottish cancer centre (Strong et al., 2008). 200 patients (71% female, mean age 56.6 years) with a cancer diagnosis who had screened positive for major depressive disorder (using the SCL-20) were randomised to a control group receiving usual care and an intervention group involving education about depression and support to cope with it and monitored over time. Persons with enduring symptoms after three months were followed-up and interviewed using a structured clinical interview. Anxiety was also measured using the EORTC QLQ C30. Depression scores were found to fall more significantly in the intervention group than in the control group at three months ($p=0.002$). These differences endured over time when measured at six and twelve months. However, patients with brain tumours were specifically excluded from participation as were other cancer patients with a poor prognosis (the majority of participants were breast cancer patients).

Variation in methods is perhaps one reason for great variation in the reported incidence of depression so that the exact figure remains unclear. The literature suggests that the presence of depression in brain tumour and other cancer patients is clear but remains untreated in many cases. The exact nature of that depression whether it be an emotional response to the disease or a direct result of organic brain disease appears to be unknown. I would argue that there is more to be gained from understanding the composite nature of depression in order to formulate interventions to detect and treat the disorder.

Appendix Three: The role of support groups in supportive care

Use of support groups as a support mechanism appears to vary individually. The role of support groups is summarised below in relation to a selection of relevant articles.

Leavitt *et al* have examined the role of a support groups for people with a brain tumour diagnosis in the USA (Leavitt et al., 1996). Members used the groups to tell their story in a safe environment and maintain morale. Topics of discussion included: managing medical advice; information seeking and exchange; coping with life changes; the long haul of the illness; and quality of life after initial treatment. The authors argue that a clinical nurse specialist role is ideal for facilitating and supporting people with a brain tumour as they can give medical advice, promote self care and provide emotional support.

Grande, Myers and Sutton have investigated the difference between those who attend support groups and those who do not among a group of 62 people (52 female, 10 male) with a cancer diagnosis attending a UK cancer community-based help centre compared with a random selection of 44 people (27 female, 17 male) from a local cancer registry (Grande et al., 2006). Beliefs about outcomes of support group participation were applied to Ajzen's Theory of Planned Behaviour (Ajzen, 1988). People who used support groups were more likely to be female, younger, have a higher level of education and have no partner than people who did not attend. Support group participants were more likely to have an active coping strategy; use planning and cognitive reframing; and have anxiety and depression. Attendees had positive beliefs about the benefits of support group participation and felt more in control of their cancer, although it is unknown whether positive beliefs were the reason for, or result of,

group attendance. Participants who did not attend support groups reported more support from a significant other person than those who attended the support group and all participants were influenced by the beliefs of others. The study was also limited to examining community based support group participation when participants from both groups were eligible to attend hospital run support groups (of which four people from the non- community support group attendees and eight from the community support groups utilised). The authors concluded that psychosocial variables were the biggest predictor of support group participation and suggested that some of these were subject to change and could increase the amount of support groups attended. However, this suggestion assumes that support groups are a desirable support mechanism for every cancer patient whereas it is unknown at present whether or not participation would be beneficial.

Ussher *et al* have explored the benefits to be gained from *peer* led cancer support groups in Australia that other supportive relationships cannot provide, responding to a lack of research in this area (Ussher et al., 2006). The authors have used observation and focus groups with 93 attendees (75 women, eight men) of nine cancer patient support groups. Members of support groups viewed support groups as a source of community and acceptance, providing a warm and empathic environment to facilitate adaptive coping as well as a source of information. People positively appraised both professionally trained and peer group leaders. These benefits contrasted with feeling isolated, ill informed and rejected outside the group. On the other hand, attendees did find it challenging and draining to deal with others' illnesses and concerns but accepted this as 'part of the journey'. In this sense, people did appreciate the opportunity to have a normal life outside of the group and viewed the relationships within and outside the group as different and almost complementary types of support. As a result of support group attendance, participants reported a positive impact on their well-being and felt that it helped them to cope, facilitating hope, optimism, empowerment, acceptance and

agency. Attendees were able to positively re-evaluate their position and strengthen their sense of identity in their lives beyond the group. Support groups appear to be an outlet for concerns and distress in contrast to living a normal life. However, this study does not explore the views of people who do not attend support groups. As Grande's study has shown, people who do not attend support groups report increased support in other areas of their life. It is possible that the participants in this study are more likely to attend support groups as they have negative supportive relationships outside of the group. Therefore, this is not an adequate reflection of supportive relationships outside of support groups as those who choose not to attend may have adequate positive support elsewhere. In addition, use of focus groups to discuss the benefits of support groups may elicit more socially desirable responses. As the authors themselves recognise, the dominant discourse in support groups is positive and so there is no room for more of a critique.

The role of social and emotional support from friends and family members, health professionals and other people with a cancer diagnosis have been shown to play an important role in reducing distress and helping people to cope with the difficulties of living with cancer.

Appendix Four: Quality in qualitative research

Traditional methods of appraisal found in quantitative research such as tests of validity and internal reliability fall short when evaluating a qualitative study where the whole purpose and objectives of the research are fundamentally different. Judging a particular interpretation of a qualitative dataset is again a subjective endeavour, making it very difficult, not least because of the number of different suggestions of approach made in the literature (Dixon-Woods et al., 2004b). There has been some debate about the extent to which qualitative research *can* be objectively evaluated due to its very subjective nature. There is also a danger of researchers resorting to ad hoc 'quick fixes' in order to comply with overly critical evaluators, as Barbour coined the phrase, a case of the 'tail wagging the dog' (Barbour, 2001). This could mean trying to fit in with a positivist ideal of what a rigorous piece of research should look like (with marks of quality such as internal validity, reliability, generalisability and replicability levied against quantitative studies) rather than engaging in a thorough design process from the outset.

However, this need not excuse qualitative research altogether. Adopting a middle way approach to one's worldview as discussed by Seale and therefore a common knowledge shared by researchers, enables agreed standards of quality in qualitative research to be set, against which trustworthiness, plausibility, credibility and relevance can be judged (Seale, 1999b). In practical terms, the process through which a set of outcomes are produced can still be subjected to close scrutiny and appraisal. The emphasis here is on transparency of approach, leaving an audit trail of what has been done and how it has been achieved. This also makes it easier to see when a good quality analysis has been done, although process and output remain distinct. Dixon-Woods *et al* argue that while in quantitative research a standard formula has been developed and widely accepted, the picture is much less clear in qualitative research and it should not be regarded as a

unified field (Dixon-Woods et al., 2004b). In addition to transparency of approach, design and analysis, other signs of credibility and quality in qualitative research include reflexivity, full use of the dataset with participant identifiers to illustrate this and insight into existing theories and developing these in relation to your dataset (Barbour, 2008b). Rosaline Barbour sets out a series of potential questions to ask when evaluating a qualitative study which serve usefully as rules of thumb when designing and conducting a study. They include questions such as 'Is a qualitative approach appropriate?'; 'Is the method/ combination of methods appropriate?'; 'How systematic was data collection?'; 'How successful has the sampling strategy been in producing the desired range/ diversity of respondents/ groups/ settings?'; 'Is the process of analysis adequately described?'; 'what reassurances are provided that data have not been selectively analysed/ presented?'; 'Do quotations/ extracts work in terms of illustrating the points made?' and 'Are the conclusions justified and useful?' [P34](Barbour, 2008b). An inclusive approach to appraising the quality of research was adopted based on the following principles derived from a study by Dixon-Woods *et al.* These principles were used to judge the quality of the background literature to consider in planning this study in addition to the ensuring the quality of my own research practices:

Are the research questions clear?

Are the research questions suited to qualitative inquiry?

Are sampling, data collection and analysis clearly described?

Are the above appropriate to the research question?

Are the claims made supported by sufficient evidence?

Are the data, interpretations and conclusions clearly integrated?

Does the paper make a useful contribution?

Source: Dixon-Woods, M., R. L. Shaw, et al. (2004). "The problem of appraising qualitative research " Quality and Safety in Health Care **13**: 223-225.

Appendix Five: Evaluation of the National Comprehensive Cancer Network Distress Thermometer (DT) and DT tool

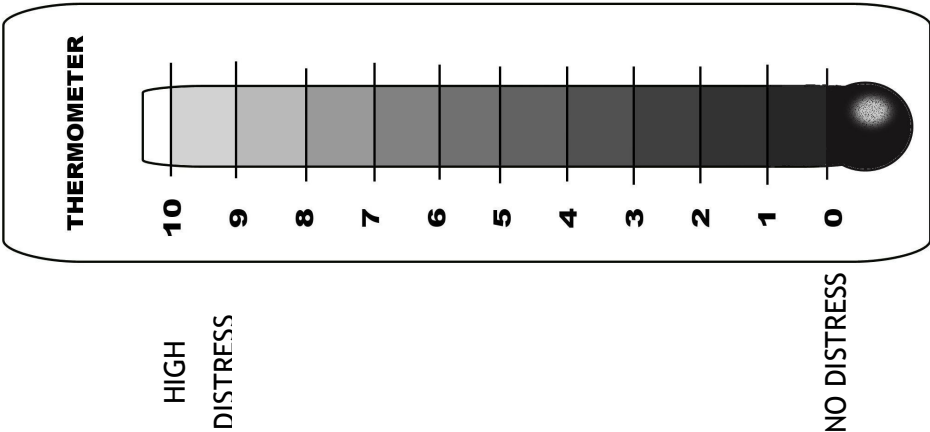
The DT has been validated by a number of studies to date. For example, Jacobsen *et al* compared the DT with Hospital Anxiety and Depression Scale (HADS) and the Brief Symptom Inventory 18 (BSI-18) in a group of patients with mixed cancer diagnoses. They found that a DT score of 4 was most sensitive in picking up distress comparable with a HADS score of 14 and a BSI-18 score of 10 for men and 14 for women (Jacobsen *et al.*, 2005). Roth found a score of 5 on the DT to be the most sensitive compared with a HADS score of 14 for men with prostate cancer, with 74.4% concordance between the two tools (Roth *et al.*, 1998). Akizuki *et al* assessed the sensitivity of the Japanese equivalent of the DT using ROC curve analysis. Again, they found a cut off of 5 to be optimal in detecting significant distress in patients with mixed cancer diagnoses who were assessed for major adjustment disorder and major depressive disorder based on a psychiatric interview (Akizuki *et al.*, 2003). Hoffman *et al* also used ROC curve analysis to compare the DT, the BSI and the BSI-18 in a sample of 68 people with various cancer diagnoses. The researchers were not able to reach a conclusion about the best cut off score to detect significant distress in patients, but sensitivity and specificity for a cut off score of 5 were similar to the other studies done (Hoffman *et al.*, 2004). Finally, Ransom *et al* validated the tool with a group of 491 bone marrow transplant patients with diagnoses of multiple myeloma, acute myeloid leukaemia and non-hodgkin's lymphoma. The DT significantly correlated with scores for distress assessed using the CES-D and STAI-S. ROC curve analysis showed that a DT cut off score of 4 had most sensitivity and specificity compared to the CES-D cut off of 16 although they concede that a score of 4 errs on the side of caution. Ransom *et al* conclude that the DT compares well with more detailed measures of psychological distress and although there is more

likelihood of false positives with a cut off score of 4, it minimizes the possibility of someone with significant distress requiring intervention being missed.

The introduction of the DT in the UK is more recent although it has been validated by studies and its use is becoming more widespread. For example, Gessler *et al* have assessed the DT to be valid compared with the HADS, BSI-18 and General Health Questionnaire 12(GHQ-12) in a group of 171 cancer and palliative care patients. The authors concluded that the DT was a valid instrument for use in the UK and could also be used to monitor changes in distress over time (Gessler et al., 2008). The Distress Thermometer's utility as a clinical tool for screening distress is currently being assessed in cancer centres around the UK.

An example of the NCCN Distress Thermometer used in this study is shown below.

First please circle the number (0-10) that best describes how much distress in general you have been experiencing over the past week, including today.



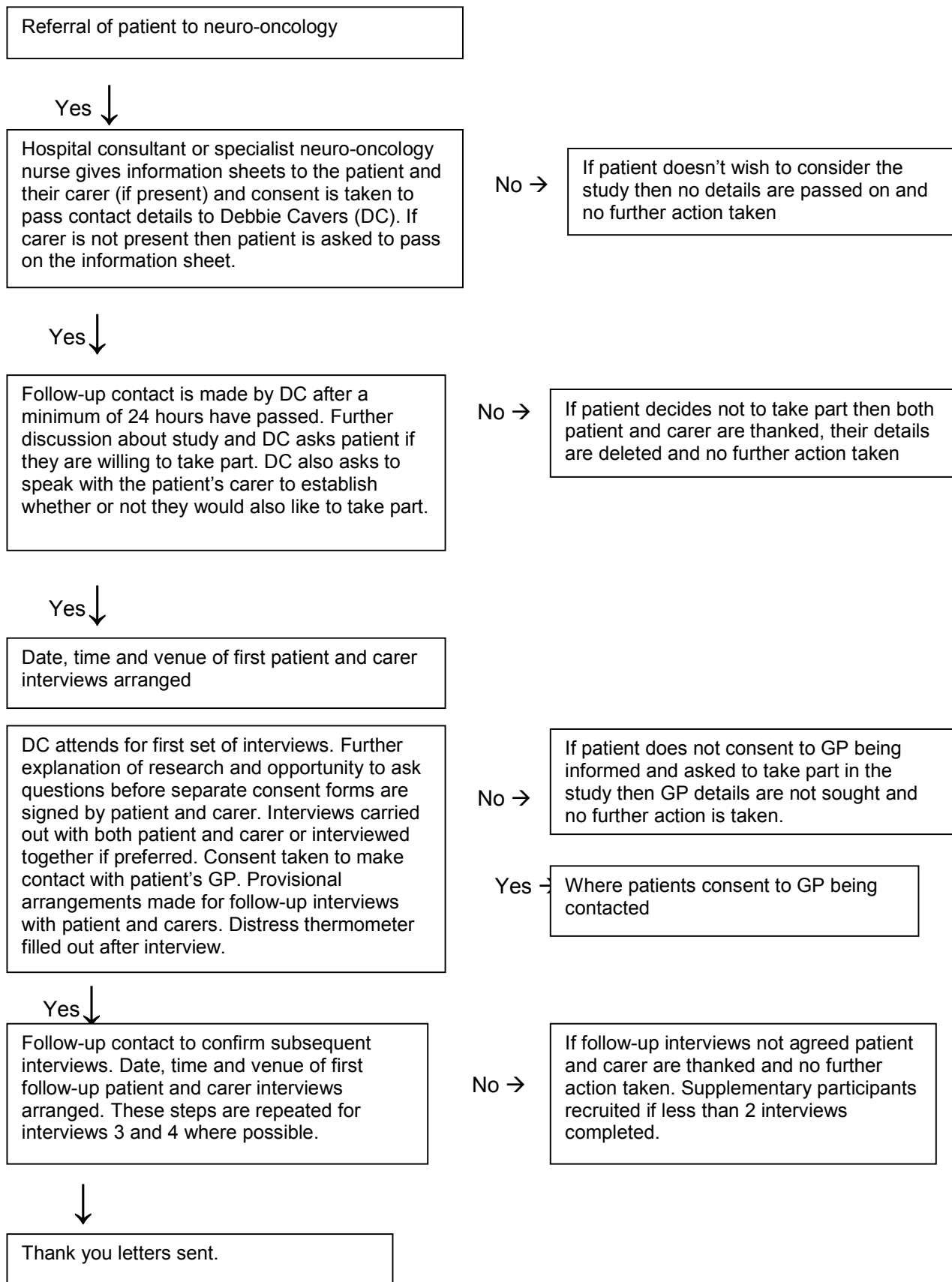
Second, if any of the following has been a problem for you over the past week, including today, please tick the box next to it. Leave it blank if it does not apply to you. Then rank your top 4 difficulties (1 would be the biggest problem, 4 would be your fourth biggest concern)

RANKING	Practical Problems	RANKING	Physical Problems
	<input type="checkbox"/> Child care		<input type="checkbox"/> Appearance
	<input type="checkbox"/> Housing		<input type="checkbox"/> Bathing/dressing
	<input type="checkbox"/> Insurance		<input type="checkbox"/> Breathing
	<input type="checkbox"/> Transportation		<input type="checkbox"/> Changes in urination
	<input type="checkbox"/> Work/school		<input type="checkbox"/> Constipation
	Family Problems		<input type="checkbox"/> Diarrhoea
	<input type="checkbox"/> Dealing with children		<input type="checkbox"/> Eating
	<input type="checkbox"/> Dealing with partner		<input type="checkbox"/> Fatigue
	Emotional Problems		<input type="checkbox"/> Feeling swollen
	<input type="checkbox"/> Depression		<input type="checkbox"/> Fevers
	<input type="checkbox"/> Fears		<input type="checkbox"/> Getting around
	<input type="checkbox"/> Nervousness		<input type="checkbox"/> Indigestion
<input type="checkbox"/> Sadness	<input type="checkbox"/> Mouth sores		
<input type="checkbox"/> Worry	<input type="checkbox"/> Nausea		
			<input type="checkbox"/> Nose dry/congested

Other problems: _____

Other problems: _____

Appendix Six: Flowchart of recruitment process for neuro-oncology patients and their informal carer



Appendix Seven: Information sheets used in the study

Information sheet for patients and relatives



Improving care for people attending neurology or neuro-oncology and their families

Information for patients

You are being invited to take part in a research study. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss with others before deciding whether or not you wish to take part. Please get in touch if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

We want to find out about the experiences of patients who have been referred to the department of neurology or neuro-oncology for a scan, a consultation or any treatment. We are interested to hear about what has happened to you, any problems you have had and any suggestions of how your experience could be improved. We want to hear about all aspects of your experience, not just the hospital part.

Why have I been chosen?

You have been chosen because you have recently been ill and referred to neurology or neuro-oncology. The doctors there think that you might be suitable to take part in the study. We hope to speak to 20 patients in a similar situation to you. We also hope to talk to the main person in your life that is sharing this experience with you. This could be your husband or wife, your partner or another relative or friend that is coming with you to the hospital or helping you in another way. We would also like to talk to your GP and other doctors and people working in the health service like nurses who have been involved or might be involved in your care in the future.

Do I have to take part?

No, you are completely free to decide whether or not you would like to take part. Your medical care will not be affected in any way no matter what decision you make. This study is completely separate from your medical treatment. If you are at all interested in taking part then you will be given this information sheet to keep and given the chance to think about it. Your contact details will be passed to the researcher, Debbie Cavers, a health psychologist, who will be in touch with you to answer any other questions and see whether or not you would like to take part. You are free to withdraw from the study at any time without giving any reason. Again, this will not affect the standard of your care in any way.

What will happen to me if I take part?

Debbie Cavers will arrange a time to come and talk to you on a date and time that is convenient to you. The interview will happen in a place that is preferable to you. Depending on where you are, this could be in your own home, in a room at the hospital or on the hospital ward if you are staying there. Debbie will come to speak to you for between 15 minutes to over an hour, depending on how much you have to say. We would also like to talk to your main relative or friend that is sharing the experience with you. Debbie will ask them similar questions in order to understand their point

of view. Or if you prefer they can be present during your interview and we can speak to them at the same time.

Debbie will ask you some questions about your experience of being ill and coming to the hospital. She will ask you about things or people that you have found helpful, things that have not been helpful and your ideas about how things could be made better for you and your family. If you agree, the interview will be recorded so that we can listen back and make sure we interpret what you say correctly. Any tapes will be stored securely and only listened to by the research team. Your interview will be typed out and transcribed. We would also like to come and speak to you again in the future if you agree. We will ask you to fill out a very brief questionnaire at the end of the interview about any problems that you have had.

What are the potential benefits of taking part?

There are no direct medical benefits to you from taking part in the study. The study aims to improve care for patients like you in the future. Hearing the views of people in your situation is vital to understanding how the whole experience can be improved. Patients who have taken part with us in previous studies have generally found it helpful.

Will my taking part in the study be kept confidential?

Your name and contact details will not be known to anyone other than the researcher and no information will be given to anyone outside of the research team. Your doctors do not need to know that you are taking part in the study if you would prefer it that way. However, we would like to speak to your GP as well as long as you are happy with this. We will not pass on any information without your permission. Anything you say in the interview will be private and confidential and no-one outside of the research team will know what you have said. Any names, places or other identifiable features will be removed so that you cannot be identified. Any quotes from what you have said to us that are used will therefore be anonymous. Recorded interviews will be stored securely and erased in due course.

What will happen to the results of the study?

We will write reports in medical and other professional journals so that doctors, nurses and other health professionals can understand the patient's perspective and hence provide better care.

What if something goes wrong?

We do not anticipate any harm occurring to you from taking part in this research. But, if something goes wrong there are no special compensation arrangements. However, if you have any complaints about the research the normal National Health Service complaints procedure will be available to you.

Who is organising the study?

The study is being organised by a team of researchers at the University of Edinburgh and the Western General Hospital. The study has been approved by the Lothian Research Ethics Committee.

Contact for further information:

If you have any questions or would like to discuss any aspect of the study before deciding to take part, you can contact Debbie Cavers on Debbie.Cavers@ed.ac.uk or telephone 0131 537 3566. If you would like to speak confidentially about this study to a doctor that is not involved, please contact GP Dr Donald Thomson on 0131 650 9496.

THANK YOU for taking the time to read this information sheet and considering this study. Please feel free to get in touch if you have any questions.

Information sheet for GPs



Improving care for people attending neurology or neuro-oncology and their families Information for General Practitioners

You are being invited to take part in a research study. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss with others before deciding whether or not you wish to take part. Please get in touch if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The study aims to improve the holistic care of people diagnosed with malignant cerebral glioma and their families. We will explore the views of patients, their main carer and the health professionals involved in their care in order to understand their experience and identify and address unmet needs. As part of the project, we aim to interview the general practitioners of each of the patients taking part in the study.

Why have I been identified?

We are interested in speaking to you because you have been identified as the general practitioner of a person diagnosed with a glioma at the Edinburgh Centre for neuro-oncology who is taking part in this research project. Your patient has given their consent for you to be contacted and asked to take part in an interview.

What does the study involve for me?

If you consent to taking part, Debbie Cavers, a health psychologist, will arrange a time to visit you at your practice or another place and time that is convenient and conduct a recorded qualitative interview. Telephone interviews can be arranged if this is preferable. The interviews are expected to last for 15-40 minutes and cover a range of topics about your experience of being involved in the care of a glioma patient. We are interested to hear about your views on how patients' care can be improved to make their lives better and on aspects of the service that could be improved in order to make it easier for you to offer them the best care possible. We are interested in hearing about how involved in your patient's care you have been and how this was facilitated or inhibited.

Your interview will be recorded and transcribed for analysis. All interview data will be confidential and anonymous with patient and doctor identifiable features removed.

What will happen to the findings of the study?

The findings of the study will be written up in the form of a report and articles published in peer reviewed journals. The recommendations made will inform health and social care provision. The findings will also inform the development of interventions to improve care for glioma patients and their families.

The study team

The study is being organised by Debbie Cavers and a team of researchers in oncology and general practice at the University of Edinburgh and the Western General Hospital. The study has been approved by the Lothian Research Ethics Committee.

Debbie Cavers
Wiseman Research Fellow
Edinburgh Centre for Neuro-oncology
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

Professor Scott Murray
Reader in General Practice
School of Clinical Sciences and Community Health
The University of Edinburgh
20 West Richmond Street
Edinburgh
EH8 9DX

Dr Sara Erridge
Senior Lecturer in Radiation Oncology
Edinburgh Cancer Centre
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

Dr Belinda Hacking
Clinical Psychologist
Edinburgh Cancer Centre
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

Dr Marilyn Kendall
Research Fellow
School of Clinical Sciences and Community Health
General Practice Section
University of Edinburgh
20 West Richmond Street
Edinburgh
EH8 9DX

Contact for further information:

If you have any questions or would like to discuss any aspect of the study before deciding to take part, you can contact Debbie Cavers on Debbie.Cavers@ed.ac.uk or telephone 0131 537 3566.

THANK YOU for taking the time to read this information sheet and considering this study. Please feel free to get in touch if you have any questions.

Information sheet for health, health-related and social care professionals



Improving care for people attending neurology or neuro-oncology and their families. Information for health, health-related and social care professionals

You are being invited to take part in a research study. Before you decide if you want to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss with others before deciding whether or not you wish to take part. Please get in touch if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The study aims to improve the holistic care of people diagnosed with malignant cerebral glioma and their families. We will explore the views of patients, their main carer and the health and social care professionals involved in their care in order to understand their experience and identify and address unmet needs. As part of the project, we aim to interview a broad range of health and social care workers including consultant, nurse specialists, social workers, community care practitioners and chaplains involved in the care of persons with a glioma.

Why have I been identified?

We are interested in speaking to you because you have been identified as a professional working in the treatment, care or support of a person diagnosed with a glioma at the Edinburgh Centre for Neuro-oncology.

What does the study involve for me?

If you consent to taking part, Debbie Cavers, a health psychologist, will arrange a time to visit you at work or another place and time that is convenient and conduct a recorded qualitative interview. Telephone interviews can be arranged if this is preferable. The interviews are expected to last for 15-40 minutes and cover a range of topics about your experience of being involved in the care of a glioma patient. We are interested to hear about your views on how patients' care can be improved to make their lives better and on aspects of the service that could be improved in order to make it easier for you to offer them the best care possible. We are interested in hearing about how involved in your patient's care you have been and how this was facilitated or inhibited. Your interview will be recorded and transcribed for analysis. All interview data will be confidential and anonymous with patient and doctor identifiable features removed.

What will happen to the findings of the study?

The findings of the study will be written up in the form of a report and articles published in peer reviewed journals. The recommendations made will inform health and social care provision. The findings will also inform the development of interventions to improve care for glioma patients and their families.

The study team

The study is being organised by Mrs Debbie Cavers and a team of researchers at the University of Edinburgh and the Western General Hospital. The study has been approved by the Lothian Research Ethics Committee.

Debbie Cavers
Wiseman Research Fellow
Edinburgh Centre for Neuro-oncology
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

Professor Scott Murray
Professor of Primary Palliative Care
School of Clinical Sciences and Community Health
The University of Edinburgh
20 West Richmond Street
Edinburgh
EH8 9DX

Dr Sara Erridge
Senior Lecturer in Radiation Oncology
Edinburgh Cancer Centre
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

Dr Belinda Hacking
Clinical Psychologist
Edinburgh Cancer Centre
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

Dr Marilyn Kendall
Research Fellow
School of Clinical Sciences and Community Health
General Practice Section
University of Edinburgh
20 West Richmond Street
Edinburgh
EH8 9DX

Contact for further information:

If you have any questions or would like to discuss any aspect of the study before deciding to take part, you can contact Debbie Cavers on Debbie.Cavers@ed.ac.uk or telephone 0131 537 3566.

**THANK YOU for taking the time to read this information sheet and considering this study.
Please feel free to get in touch if you have any questions.**

Appendix Eight: Ethics approval letter

Lothian Local Research Ethics Committee 02

Telephone: 0131 536 9061

Facsimile: 0131 536 9346

18 May 2006

Mrs Debbie G. Cavers
Wiseman Research Fellow
University of Edinburgh
Edinburgh Centre for Neuro-Oncology
Western General Hospital, Crewe Road South
Edinburgh
EH4 2XU

Dear Mrs Cavers

Full title of study:	Improving care for people living with glioma: understanding the support needs of glioma patients and their families. A qualitative study.
REC reference number:	06/S1102/13

Thank you for your letter of 23 April 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 2 May 2006.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.1 (2)	17 March 2006
Investigator CV	1	16 March 2006
Protocol	1	15 March 2006
Covering Letter		23 April 2006
Summary/Synopsis	1	15 March 2006
Summary/Synopsis	1	15 March 2006
Summary/Synopsis	1	15 March 2006
Letter from Sponsor		08 March 2006
Compensation Arrangements		15 March 2006
Interview Schedules/Topic Guides	1	02 March 2006
Interview Schedules/Topic Guides	1	02 March 2006
Interview Schedules/Topic Guides	1	02 March 2006
Questionnaire		16 March 2006
Letter of invitation to participant	1	16 February 2006
GP/Consultant Information Sheets	1	14 March 2006
Participant Information Sheet	1	21 February 2006
Participant Information Sheet	1	16 February 2006
Participant Information Sheet	1	16 February 2006

Participant Information Sheet	2	23 April 2006
Participant Consent Form	1	23 February 2006
Participant Consent Form	1	23 February 2006
Participant Consent Form	1	23 February 2006
Participant Consent Form	1	23 February 2006
Participant Consent Form	1	23 February 2006
Response to Request for Further Information		23 April 2006
Supervisor's CV		16 March 2006
Letter from Funder		09 March 2006

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/S1102/13

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Professor Peter Hayes

Chair

Email: lyndsay.baird@lhb.scot.nhs.uk

Appendix Nine: Recruitment letters to GPs and other health, health-related and social care professionals

Letter for GPs

Edinburgh Cancer Research Centre
SCHOOL *of* MOLECULAR & CLINICAL MEDICINE
The University of Edinburgh

Debbie Cavers
Wiseman Research Fellow
Edinburgh Centre for Neuro-oncology

Western General Hospital
Crewe Road South
Edinburgh EH4 2XU

Fax + 44 (0)131 537 2659

Email: Debbie.Cavers@ed.ac.uk

Telephone + 44 (0)131 537 3566

Date

Dr _____

Address line 1

Address line 2

Address line 3

City

Postcode

Patient's name, DOB and address

Dear Dr _____

As you may know, your above patient _____ is currently being treated at the Edinburgh Centre for Neuro-oncology at the Western General Hospital in Edinburgh for a diagnosis of _____.

_____ has agreed to take part in a research study and has identified you as the GP most involved in their care. We would also like to interview you as part of the research project.

This study has been funded by the private donation of the widow of a past patient in the department who would like to improve the service and care offered to families living with a diagnosis of glioma in the future. We are conducting a series of interviews with glioma patients, their carers and one-off interviews with the health and social care professionals involved in their care. The patient and carer interviews aim to promote understanding of the experience of living with a glioma and identifying the unmet needs of patients and their families. The health and social care professional interviews (including GPs, consultants, nurses, psychologists, community practitioners, social workers and chaplains) aim to explore the views of those caring professionally for glioma patients on issues such as how the patients and families experiences can be improved and how services can be improved in order for you to facilitate the best care possible for this patient group and their carers.

We would very much appreciate it if you could take the time to read the enclosed information sheet giving further details about the study. Debbie Cavers will be in touch with you in the next week or two in order to discuss the study further and establish whether or not you are willing to take part. If you are, a brief face-to-face or telephone interview will be arranged at a time and place that is convenient to you.

Many thanks for you time.

Best wishes

Debbie Cavers

Recruitment letter to health, health-related and social care professionals

Edinburgh Cancer Research Centre
SCHOOL *of* MOLECULAR & CLINICAL MEDICINE
The University of Edinburgh

Debbie Cavers
Wiseman Research Fellow
Edinburgh Centre for Neuro-oncology

Western General Hospital
Crewe Road South
Edinburgh EH4 2XU

Fax + 44 (0)131 537 2659

Email: Debbie.Cavers@ed.ac.uk

Telephone + 44 (0)131 537 3566

Date

Title _____

Address line 1

Address line 2

Address line 3

Dear _____

A team of researchers from the University of Edinburgh are conducting a study to explore the experience of living with a malignant cerebral glioma for patients and their families to

improve service provision and holistic care. We would like to speak to you as a health, health-related or social care professional involved in the care of glioma patients for a short interview.

This study has been funded by the private donation of the widow of a past patient who would like to improve the service and care offered to patients with brain tumours and their families. We are conducting a series of interviews with glioma patients, their carers and one-off interviews with the health and social care professionals involved in their care. The patient and carer interviews aim to promote understanding of the experience of living with a glioma and identifying the unmet needs of patients and their families. The health and social care professional interviews aim to explore the views of those caring professionally for glioma patients on issues such as how the patients' and families' experiences can be improved and how services can be improved in order for you to facilitate the best care possible for this patient group and their carers.

We would very much appreciate it if you could take the time to read the enclosed information sheet giving further details about the study. Debbie Cavers will be in touch with you in the next week or two in order to discuss the study further and establish whether or not you are willing to take part. If you are, a face-to-face or telephone interview will be arranged at a time and place that is convenient to you.

Many thanks for your time.

Best wishes

Debbie Cavers

Appendix Ten: Interview topic guides

Interview topic guide for patients and carers

Interview strategy

Given the exploratory nature of the study, the interview will be flexible and sensitive to the cues of the participant. It is essential to establish a good rapport with the respondent and to use their own language to explore their illness experience rather than imposing too rigid a framework. The interview will use patient cues to move the interview forward and will only introduce certain topics if appropriate.

I just want to be sure that you are happy with what this interview involves? I will ask you a few questions about your/ your husband/ wife/ partner/ friend's illness and the experiences you have had with it. I don't want the session to be too formal and I really just want to hear what you have to say so we can learn from your experiences.

You are free with to withdraw at any time.

Everything you say will be treated confidentially.

Some of the things I might ask you to talk about are quite personal so bear in mind that you don't have to answer any questions you are not comfortable with.

Let me know if there are any questions that you don't want to answer or if you feel tired or upset in any way then we can stop.

Can I just check that you are happy to go ahead and for me to record the interview?

Do you have any questions you would like to ask?

How are you feeling in yourself today?

Can you tell me from the beginning about how you became ill?

Physical

Can you tell me about your physical symptoms?

Do you think they have had an affect on how you live your life day to day?

Is there anything that you have found difficult to deal with?

Is there anything that has helped you to deal with them in any way?

What have the professionals said to you about your illness and what you can expect?

Staff and services

Can you tell me which health services you are in contact with so far?

And are you finding them?

Are there any services that are particularly good?

Are there any services that are particularly bad?

Have you found ways to deal with this?

What are they?

How did you find out about these services?

What other kinds of help and support (social services, aids and equipment, benefits, nursing support) are you receiving?

Are there any services you feel you need that you are not receiving?

Any specific services or support for people in your situation/ with your diagnosis?

Are there any doctors, nurses or other health care staff that you are in touch with that are particularly helpful?

In what way?

Is there anybody that is not helpful?

In what way?

Do you feel that you have a plan for your ongoing care?

Where would you like to be cared for? - for later interviews.

Practical

Do you have any practical problems with day to day living since you have become ill?

Do you find it difficult to get around from place to place?

Do you have any problems getting to the hospital, GP or anywhere else related to your treatment?

Do you have any problems getting to work?

Do you find it difficult to get work done?

Do you find it difficult to find people to help you with the children at all?

Is there anything you did before you were ill that you have problems with now?

Could you say a bit more about that?

Financial

Do you have any problems with money since becoming ill?

Do you know if you have any benefits available to you?

How did you find out about them?

Have you found this helpful or not?

Are there any other concerns or issues you have related to finances?

Information and communication

Have you received any packs of information, leaflets or anything like that?

Are you happy with the level of information?

Is there anything that isn't useful?

Is there anything you particularly value?

Are there any other forms of information you would have liked that you did not receive?

What are they?

Communication -

Do you feel happy with the way the way the doctors have talked with you so far?

Have they given you enough information?

Have they talked to you in a way that you have been happy with?

Is there anything they could have said or done that would have made the consultation easier for you?

What about the time you received your diagnosis? Do you feel the doctor told you about this was okay? How could it have been better?
Is there anything you wish you did/ would like to do differently when consulting the doctor/ other healthcare staff.

Social/ family

How has your illness affected your life?
Are there family and friends in your life that have played an important role during your illness?
Are there people beyond your immediate family?
Are there any people with whom you have had a difficult time with in relation to your illness?
 Could you say why you think that is?
Are there aspects of handling social activities that have been difficult in any way?
 Could you tell me a bit more about that?
Have you had any problems in dealing with your partner?
Have you had any problems in dealing with your children or other family/ friends?

Psychological/ emotional

Have you found dealing with your illness hard to cope with?
 What has helped you to cope?
 What have been the most difficult things to cope with?
Do you have any issues that have worried you?
Is there any aspect of your illness that scares you?
 Have you felt that there is someone to talk to about this or help in any way?

Are you scared of dying? (if the issue of death and dying has been raised by the participant)

Spiritual/ existential

Would you describe yourself as a spiritual person?
Have you drawn on any aspect of this to help you deal with your illness?
Would you say you are a religious person?
 Could you tell me a bit about your religious faith and the role this has played for you?
Would you say this has helped you or not?
 How has it helped?
What religious supports would you like available over the next months/ years?
Do you feel that your faith is recognised and supported by the services you have been in contact with?
Is religious support available to you when you were/ are in hospital?
 Does this concern you?
 Could you say a bit more about why this is?
Do you ever think 'Why me?'

Service improvements

Do you have any suggestions about how all services could be improved for people in your situation in the future?

Do you feel your family could have been helped more? How?

Do you feel anything else could be done to make your life better? (your day-to-day life, your quality of life)

Is there anything that could make your life easier?

Is there anything else you would like to say about any aspect of your experience? Do you want to add to anything that has already been said?

Taking part in interviews

How did you feel about taking part in this interview?

Did you feel it was difficult for you?

Did you feel it was a comforting experience or not?

Did you feel it was a positive or negative experience?

Thank you for taking part in this interview.

Carers interviews

Carers' interviews will be in a similar format to the patient interviews asking similar questions in relation to their experience as a carer. Additional questions will be asked about the experience of caring for a loved one.

What is it like to be a carer for _____? What are the physical, emotional, stress-related implications? Have you received sufficient information?

How would you see your role in sharing _____'s experience?

Have you experienced any difficulties?

How have you dealt with these?

Have you felt supported in your role?

By whom?

Have you felt your role has changed as time has gone on? How?

Subsequent interviews

Subsequent interviews will cover similar topics to see how people's experiences have changed and what their main issues are at the stage they are at.

What are your main concerns at this stage?

Interview topic guide for GPs

Interview strategy

Given the exploratory nature of the study, the interview will be flexible and responsive to the cues of the participant, rather than imposing too rigid a framework. The interview will use respondents' cues to move the interview forward and will only introduce certain

I just want to be sure that you are happy about the purpose of the interview and what it involves? I will ask you a few questions about your views and experiences as a professional carer of glioma patients. I don't want the session to be too formal and I really just want to hear what you have to say so we can learn from your experiences. Please let me know if you are not happy to answer any of the questions and you are free with to withdraw at any time.

Can I just check that you are happy to go ahead and for me to record the interview?

Do you have any questions you would like to ask?

Can you tell me a bit about your background and your role in caring for people (the patient's name)?

Can you say a bit more about what that involves?

Are you also the GP for (carer's name)?

Could you perhaps tell me about what happened when (patient) first presented to you?

Do you have any comments or reflections on this?

Have you had any further involvement with your patient since they were referred to neuro-oncology?

How have you found that?

Have you experienced any difficulties?

Could you tell me a bit about the other health and social care professionals that are involved in the multi-disciplinary care of the glioma patient throughout their illness?

Who are the 'key players' in your view?

Do you feel that you play an important role in this team?

Are there any ways in which this team working could be improved?

Could you say a bit more about that?

Are there any aspects of the service that have made it difficult for you to be involved?

Are you happy with the level of information that you have been provided with from other sectors of the health and community care service?

What else would you have liked to be informed about?

Are you in regular contact?

How would you like to see this service improved?

Have you experienced any other communication problems with the secondary/ tertiary/ community care team?

How do you feel this could be avoided or improved?

What are your views on the current service provision for patients with glioma and their families?

Do you have any suggestions on ways in which the service could be improved?

Is there anything that could make your life easier as a GP/ consultant/ nurse/ social worker/ chaplain etc. to help provide better care for people with glioma?

Do you feel that *all* of the patients' needs are being met?

Which needs do you feel are not being addressed?

How do you think these needs could be met?

Do you think that carers' needs are being met?

How do you think carers' needs could be better recognised and addressed?

Do you think it is the responsibility of the health service to provide for *all* of the patient's needs?

Do you think it is the responsibility of the health service to provide for *all* of carers' support needs?

Is there anything else you would like to say about the service provision for people living with glioma?

Do you think there are there any other ways in which patient and family care could be improved that we haven't talked about?

Are there any other ways that the service could be improved to make it easier for you to provide that care?

Many thanks for taking part in this interview.

Interview topic guide for health and social care professional interviews

Interview strategy

Given the exploratory nature of the study, the interview will be flexible and responsive to the cues of the participant, rather than imposing too rigid a framework. The interview will use respondents' cues to move the interview forward and will only introduce certain topics if appropriate.

I just want to be sure that you are happy about the purpose of the interview and what it involves? I will ask you a few questions about your views and experiences as a professional carer of glioma patients. I don't want the session to be too formal and I really just want to hear what you have to say so we can learn from your experiences.

Please let me know if you are not happy to answer any of the questions and you are free with to withdraw at any time.

Can I just check that you are happy to go ahead and for me to record the interview?
Do you have any questions you would like to ask?

Can you tell me a bit about your background and your role in caring for people with glioma and their families?

Can you say a bit more about what that involves?

Have you had any further involvement with your patient since they were referred to neuro-oncology?

How have you found that?

Have you experienced any difficulties?

Could you tell me a bit about the other health and social care professionals that are involved in the multi-disciplinary care of the glioma patient throughout their illness?

Who are the 'key players' in your view?

Do you feel that you play an important role in this team?

Are there any ways in which this team working could be improved?

Could you say a bit more about that?

Are there any aspects of the service that have made it difficult for you to be involved?

Are you happy with the level of information that you have been provided with from other sectors of the health and community care service?

What else would you have liked to be informed about?

Are you in regular contact?

How would you like to see this service improved?

Have you experienced any other communication problems with the primary/ secondary/ tertiary/ community care team?

How do you feel this could be avoided or improved?

What are your views on the current service provision for patients with glioma and their families?

Do you have any suggestions on ways in which the service could be improved?

Is there anything that could make your life easier as a GP/ consultant/ nurse/ social worker/ chaplain etc. to help provide better care for people with glioma?

Do you feel that *all* of the patients' needs are being met?

Which needs do you feel are not being addressed?

How do you think these needs could be met?

Do you think that carers' needs are being met?

How do you think carers' needs could be better recognised and addressed?

Do you think it is the responsibility of the health service to provide for *all* of the patient's needs?

Do you think it is the responsibility of the health service to provide for *all* of carers' support needs?

Is there anything else you would like to say about the service provision for people living with glioma?

Do you think there are there any other ways in which patient and family care could be improved that we haven't talked about?

Are there any other ways that the service could be improved to make it easier for you to provide that care?

Many thanks for taking part in this interview.

Appendix Eleven: Consent forms

Patient consent form



Centre number:
Study number:
Patient identity number:

CONSENT FORM FOR PATIENTS Ver 1 23rd February 2006

Understanding the support needs of patients attending Neurology or the Edinburgh Centre for Neuro-oncology and their families

Researcher: Debbie Cavers

		Please initial
1.	I confirm that I have read and understand the information sheet dated (version.....) for the above study and have been able to ask questions.	
2.	I understand that my participation is voluntary and I am free to stop or withdraw at any time, without giving any reason, and without my medical or legal rights being affected.	
3.	I agree to my interview being tape-recorded and written down (transcribed) and understand that any written version will be anonymous (my/ our names will not appear on the written versions). I will have the opportunity to review the transcript if I request.	
4.	I agree to my GP being informed about the study and being asked to take part.	
5.	I agree to a written version of my/our interview being stored carefully without my name on it.	
6.	I wish to receive a copy of the results of this study.	
7.	I agree to take part in the above study.	

_____ Name of participant	_____ Date	_____ Signature
_____ Name of person taking consent (if different from researcher)	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

Relative consent form



Centre number:
Study number:
Patient identity number:

CONSENT FORM FOR RELATIVE/ FRIEND Ver 1 23rd February 2006

Understanding the support needs of patients attending Neurology or the Edinburgh Centre for Neuro-oncology and their families

Researcher: Debbie Cavers

		Please initial
1.	I confirm that I have read and understand the information sheet dated (version.....) for the above study and have been able to ask questions.	
2.	I understand that my participation is voluntary and I am free to stop or withdraw at any time, without giving any reason, and without my medical or legal rights being affected.	
3.	I agree to my interview being tape-recorded and written down (transcribed) and understand that any written version will be anonymous (my/ our names will not appear on the written versions). I will have the opportunity to review the transcript if I request.	
5.	I agree to a written version of my/our interview being stored carefully without my name on it.	
6.	I wish to receive a copy of the results of this study.	
7.	I agree to take part in the above study.	

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Health, health-related and social care professional consent form



Centre number:
Study number:
Patient identity number:

CONSENT FORM FOR HEALTH, HEALTH-RELATED AND SOCIAL CARE
PROFESSIONALS INVOLVED IN CARE OF NEURO-ONCOLOGY PATIENTS
Ver 1 23rd February 2006

Understanding the support needs of patients attending the Edinburgh Centre for Neuro-oncology and their families: health and health-related professional interviews

Researcher: Debbie Cavers

		Please initial
1.	I confirm that I have read and understand the information sheet dated (version.....) for the above study and have been able to ask questions.	
2.	I understand that my participation is voluntary and I am free to stop or withdraw at any time, without giving any reason, and without my legal rights being affected.	
3.	I agree to my interview being tape-recorded and transcribed and understand that the transcript will be anonymous.	
4.	I agree to a written version of my interview being stored carefully and anonymously.	
5.	I wish to receive a copy of the results of this study.	
6.	I agree to take part in the above study.	

Name of participant Date Signature

Name of person taking consent Date Signature
(if different from researcher)

Researcher Date Signature



































Appendix Twelve: List of health, health-related and social care professionals interviewed

Neurosurgeon
Neuro-oncologists (2)
Neuropsychologist
Neurologists (3)
Nurse practitioner DCN
Specialist nurse Neuro-oncology (2)
Specialist nurse oncology
Physiotherapists (3)
Occupational therapists (2)
Chaplains (2)
Maggie's centre staff (4)
Mcmillan nurses (5)
Social worker (2)
Consultants in palliative medicine (5)
Speech and language therapist
Staff nurses chemo
Staff nurse oncology
Radiographers (2)
Radiologist
General physician (Acute Receiving Unit)
Manager of oncology services (2)
Hospice nurses (2)
Clinical psychologists (2)

Appendix Thirteen: NVivo coding framework

Example from the coding frame used at time three, having been developed using all data from time one:

Name	Sources	References
Carers concerns	9	123
After loved one is gone	1	3
Carer's own health problems	3	3
Caring role	9	63
Acceptance of caring role	2	4
Difficulties of caring role	6	15
Control or power to help	5	37
Dealing with changes in loved one	6	36
Impact on carers' lives	2	26
Professionals carers and issues related	2	3
Respite	4	9
Strained relationship with loved one	5	23
Changes over time	1	1
Communication	10	46
Bedside manner	8	20
Jargon	1	1
Communication between health professionals	1	2
Communication breakdown	3	3
Importance of reassurance from health pros	2	10
Mixed messages	3	5
Reading between the lines	0	0
Receiving a diagnosis or bad news	9	32
Having someone with you - support	2	4
Prognosis	6	10
Surroundings when communicating difficult, sensit	0	0
Talking about illness	4	6
Confusion	6	11
Contact with services	9	15
Contact with community palliative care nurse	3	5
Contact with district nurse	2	5
Contact with emergency services	1	1
Contact with GP	8	10
Contact with Hospice	1	2
Contact with hospital	3	3
Contact with neuropsychologist	1	1
Contact with NHS24	1	1
Contact with nurse specialist	3	3
Contact with OT	2	2
Contact with other health professionals	3	4
Contact with physio	2	2
Contact with social services	1	3
Contact with speech therapist	1	1

Name	Sources	References
 Coping	10	211
 Acceptance	8	24
 Anger and frustration	6	43
 Anxiety or worry	9	61
 Change in appearance	2	4
 Comparison with others	3	9
 Coping strategies used	5	34
 Humour	3	3
 Denial	3	15
 Different coping strategies	3	10
 Disavowal	4	10
 Fighting spirit or staying positive	8	17
 Having a holiday	2	3
 Influence of past experiences	6	18
 Keen to get on with treatment	6	21
 Making sense of things	3	15
 Not thinking about it at all	4	8
 Relationship between patients and carers	9	40
 Influence of partners' attitude	4	10
 Protecting loved ones or concern	6	15
 Relief or Euphoria after the op	3	5
 Taking it as it comes or living in the moment	8	26
 The shock or 'out of the blue'	7	31
 Death and dying	9	44
 Any time left is a bonus or making the most of time	4	18
 Fears	5	16
 Getting affairs in order	5	26
 Concern for family	3	10
 How long have I got	5	14
 Preferred place of care	2	3
 Thinking about the future or making plans	7	34
 Distress	10	92
 Existential and spiritual issues	7	31
 Appreciating nature	1	1
 Philosophy on life or Changing outlook on life	3	16
 Religious faith	2	6
 Why me	2	9
 Experience of being in hospital	8	21
 Hospice care	1	1
 Lack of control or comfort of own home	2	3
 Privacy	0	0

Name	Sources	References
Faith in medical profession or NHS	8	31
Financial support and issues	5	22
Hope	9	50
Information	9	92
Ability to absorb information	7	18
Having someone with you - information	3	3
Readiness for information	2	7
Assumptions about what patients know	0	0
Building the medical framework to pin information	6	47
Desire for clear and direct information	8	18
Differing information needs	3	11
Information needs	9	55
Information not tailored or specific	5	9
Information provided or good quality information	9	39
Information reduces distress	5	14
Lack of information	6	29
Being kept in the dark	5	11
Other sources of information or support	5	31
Consulting friend or family experts	3	13
Poor quality information	4	7
the Internet as a source of information	3	14
Too much information can be a bad thing	3	4
Managing and controlling illness	10	127
Acceptance of caring role	3	14
Aids provided or sourced and used	5	23
Loss of independence or dignity	8	26
Managing and dealing with symptoms	8	59
Other peoples' attitudes and expectations	4	13
Medication and treatments	10	88
Expectations from treatment	9	25
Experiences of having treatment	6	18
perceived side effects of treatment	10	27
Negative experiences	5	21
Normality	9	79
Adaptation	9	67
Changing role and identity	10	51
Dealing with new abilities and adaptati	10	45
Importance of Quality of Life	6	17
Adjustment	9	58
Attempts to get back to normal	8	44

	Name	Sources	References
	Impact on personal or social life	9	55
	Impact on work	9	35
	Not being able to drive	2	4
	Physical or cognitive symptoms and side effects.	10	151
	Co-morbidities	0	0
	Dealing with physical symptoms	9	67
	Fatigue	9	25
	Feeling fine. No symptoms.	4	14
	Improving condition	5	24
	Memory and other cognitive deficit	4	12
	Pain	4	14
	Personality and behaviour changes	4	32
	Physical or cognitive decline	6	25
	Seizures	1	1
	Practical issues	9	34
	Process of reaching a diagnosis	6	11
	Delays in reaching a diagnosis	2	2
	Diagnosis narrative	5	5
	Initial misdiagnosis	3	3
	Investigations and tests	3	4
	Satisfaction with services	8	23
	Social and emotional support	10	84
	Maggie's centres	3	8
	Managing extended family and friends	8	17
	Managing children	4	11
	Strained relationships with families and	3	6
	Other peoples' experiences	5	14
	Negative impact of other peoples' stori	4	9
	Role of the family	10	46
	Support from other patients	1	2
	Support groups	2	2
	Suggested improvements	8	29
	Areas of dissatisfaction	6	26
	The hospital buidling	1	2
	Support for children	4	8
	Taking part in interviews	8	13
	Difficulties in taking part	2	2
	Communication problems	0	0
	Emotionally distressing	1	1
	Tiredness	1	1
	If it helps someone else	4	4

	Name	Sources	References
	Importance of research	2	2
	Neutral	4	4
	Personally beneficial	4	8
	Getting it off your chest	2	2
	Making sense of it all	2	3
	Therapeutic	2	2
	Timings	3	30
	Delays	3	5
	Things moving quickly	2	3
	Waiting	4	31
	Transport	4	7
	Uncertainty	8	37
	Limbo	3	4
	Not knowing what to expect	5	15
	Uncertainty after treatment	1	1

Appendix Fourteen: Ethical dilemma when conducting multi-perspective interviews: a case study

Conducting multi-perspective longitudinal interviews with patients and their relatives can raise complex ethical issues, and this case exemplifies this. A bereaved wife requested to listen to recorded interviews between myself and her late husband. Latterly, the patient had lost his ability to speak and thus converse with his family. As his illness progressed, the couple did not talk to one another about what they were going through. They each took part in separate in-depth qualitative interviews in which they spoke to me about how they felt and were dealing with their situation. Both parties had read the information sheet and consented to taking part in a *confidential* study where their anonymity would be safeguarded. However, since his death a year previously, his wife had been struggling to come to terms with her loss. She asked to listen to the interviews in order to understand what he was going through at the time, to help her accept his death and deal with her overwhelming grief.

This request raised both legal and ethical considerations. I consulted my wider research group and we decided to consider it as a case conference including: oncologist, GP and psychologist in the research team, supported with advice from the local research ethics committee and the University Professor of Medical Ethics. The four principles of medical ethics – beneficence, non-maleficence, respect for autonomy and justice – were used to inform the decision. Relevant questions included:

What was the legal stance on allowing access?

What were the moral and ethical implications and ramifications either way?

What would the patient have wanted under the circumstances?

Could the patient be harmed or benefit?

What is the bereaved relative's motivation to listen to the interviews?

What was the potential harm or benefit to the bereaved relative either way?

No harm could come to the deceased patient, but allowing access to the recordings could be considered a breach of respect for his autonomy. I also felt, based on my knowledge of the couple, that the patient would have allowed access to the recordings to help his wife if he could. There was potential for harm to the bereaved wife if she was not allowed access to the recordings, if only because of the benefit she perceived she would gain. There was also potential for inadvertent harm to her from listening to the recordings but I did not think there was anything overtly harmful in the content of the interviews. There was potential for her to benefit from listening to the interviews if they provided the comfort and information that she needed. However, I suspected her grief was more complex and a psychological referral was made to help her address this.

The research ethics committee informed me that I was under no legal obligation to release the information – section 27 (2) of the Freedom and Information Act stated that any information obtained or derived from a programme of research is exempt from access to information after death. However, the standard advice from the BMC 'Medical Ethics Today' [2004: P514] asserts that the law relating to confidentiality of identifiable data about deceased people for research is the same as in other health care contexts. Here, the Access to Medical Records Act 1990 allows limited rights of access to the records of deceased people, and the deceased person's human rights do not apply after death. There was no guidance stating that I had to release the information, suggesting the decision was ultimately an ethical one. The BMC Medical Ethics Today suggests that decisions should be made at the doctor's discretion based on their assumption of the deceased person's former wishes and the use to which the information would be put. It was a case of weighing up the potential harm of releasing the information with the benefit to be gained from doing so.

It was decided after some consultation and consideration that the recordings would be released. We felt that the potential harm to the bereaved wife from not hearing them (including her perception of what was contained in the recordings) had more profound consequences than the potential for harm – and greater potential for benefit – from listening to the recordings. However, it was important that this situation was handled safely to ensure her best interests were upheld. We decided to respect her privacy when listening to the recordings but a follow-up appointment was made with a psychologist to discuss this with her. Thankfully there was a positive outcome in this situation. This case study illustrates the potential complexity of ethical decision-making and responsibility when conducting social research.

Appendix Fifteen: Co-authored published journal articles evaluating multi-perspective and qualitative longitudinal methods

Online links to the articles:

URL to multi-perspective paper: <http://www.bmj.com/cgi/content/full/bmj.b4122>

URL to QLL paper: http://www.bmj.com/cgi/content/full/339/sep28_1/b3702

Full text of the articles to follow

RESEARCH METHODS & REPORTING

Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs

Marilyn Kendall, Scott A Murray, Emma Carduff, Allison Worth, Fiona Harris, Anna Lloyd, Debbie Cavers, Liz Grant, Kirsty Boyd, Aziz Sheikh

A better understanding of the needs of patients and their carers can help improve services. **Marilyn Kendall and colleagues** describe how to conduct multiperspective studies

Centre for Population Health Sciences: General Practice Section, University of Edinburgh, Edinburgh EH8 9DX

Correspondence to: M Kendall
Marilyn.Kendall@ed.ac.uk
Accepted: 3 August 2009

Cite this as: *BMJ* 2009;339:b4122
doi: 10.1136/bmj.b4122

Linked interviews conducted with patients and their informal and professional carers can generate a richer understanding of needs and experiences than the single perspective most commonly used in qualitative studies. Interview dyads or triads, where two or three participants are interviewed as a set or case study, can explore complex complementary as well as contradictory perspectives, and there is considerable scope for using this method in a range of long term conditions.

Based on our experiences of conducting multiperspective studies and drawing on the wider literature, we summarise when researchers might find multiperspective interviews a useful approach, discuss how to use this approach, consider the data that are generated, and highlight potential pitfalls and how to avoid these.¹⁻⁵ This paper builds on our previous article discussing the need for longitudinal qualitative approaches.⁶ Combining longitudinal and multidimensional interviews can prove particularly valuable.

When are multiperspective interviews appropriate?

Multiperspective interviews are potentially most useful when seeking to

- Understand relationships and dynamics among patients, their families, and professional carers
- Explore similarities and differences in the perceptions of patients and their family and professional carers
- Understand the individual needs of patients, carers, and professionals
- Integrate suggestions for improving services from patients, carers, and professionals.

We have used the approach mainly in the context of pallia-

tive care, where family and professional carers have an important role (table).¹⁻⁵ Other researchers have shown the value of a multiperspective approach in diverse clinical areas including the pattern of symptoms in childhood cancer; the couple's experience of breast cancer recurrence and prostate cancer; the complex clinician-patient interactions around requests for physician-assisted suicide; and development of a model of care giving skills for relatives of people with cancer.⁷⁻¹¹

Dyad combinations typically include husband-wife, mother-child, and patient-carer. Triad combinations, as in a study exploring children's, parents', and professionals' views about tissue donation for research, have been used far less often.¹² In a study of patient-family dyads about information disclosure, the researchers concluded that interview triads would have given broader and deeper information.¹³ More recently, another study used interviews with patients, carers, and professionals to explore views about when prognostic discussions should be instigated.¹⁴

How do you conduct multiperspective interview studies?

Recruitment

Our experiences have highlighted the value of a stepwise approach starting with the patient, then recruiting an informal carer, and finally health or social care professionals. Before patients give their consent, they understand that they will be invited to nominate the family members and professional carers who are most important or central to their care. The aim is to recruit those informants most likely to have relevant information for the study. Consent is obtained from each individual in turn. The aim is to complete a set of interviews over a few days or weeks, ensuring that all participants have the opportunity to reflect on whether they wish to participate and are clearly informed that they are free to withdraw at any time without adversely affecting their or their family's care and support. We found that patients were happy and able to recommend a range of key informal carers and professionals for interview. When approached in this way, the majority of carers were willing to participate.

Data generation

We usually begin by interviewing the patient alone and then the family carer in order to generate separate accounts. However, in about half the cases in our palliative care studies the patient and family carer preferred to be interviewed together. Although this can constrain the discussions, at other times

SUMMARY POINTS

Case linked interviews with patients and their carers can generate a richer understanding of needs and experiences. Such studies can provide practical recommendations about how to deliver services. Serial multiperspective interviewing is particularly valuable in understanding changes over the course of an illness.

patients and carers were able to prompt each other to mention or expand on specific issues or experiences. Interviewing the carer simultaneously also has the advantage of allowing additional insights into the relationship. We typically interview professionals last and have found that telephone interviews, which can easily be recorded using a telephone adaptor, are the most efficient and acceptable method.

Analysis

Analysis proceeds concurrently with data generation, allowing emerging themes and concepts to be reflected on with subsequent participants. Interview transcripts and field notes from each set of patient, family, and professional carer can, however, be analysed as separate case studies and then as groups of case studies. Even a small sample will generate a variety of analytical opportunities, so qualitative software such as NVivo (www.qsrinternational.com) can be useful in organising these data.

If a longitudinal, serial dyad or triad approach is used, analysis may also be undertaken across all first interviews, then across all second and subsequent sets of interviews, or by synthesising data relating to specific key points or transitions, such as interviews with patients approaching the last days of life. By coding within as well as between cases, changes over time linked to particular patients and their associated carers and professionals can be retained and analysed in considerable depth. The context of individual patient journeys is preserved while undertaking the broader thematic analysis.¹⁵ Creation of a matrix linking cases to the coding frame can help writing and interpretation, maximising the strengths of multiperspective data.

What type of findings might you expect?

Understanding of relationships and dynamics

Multiperspective interviews can enhance understanding of

interactions such as patient-carer-doctor relationships or provide rich insights into the multifaceted roles of patients within their families and communities and the way in which these serve to maintain their identity. In one case, we conducted interviews with the patient, his wife, a specialist nurse, the church minister, his general practitioner, and an overnight nurse to develop a complex account of the experience of dying at home from lung cancer.¹⁶

Comparison of perceptions of patients, their family, and carers

Interviews with patient, family, and professional sometimes show concordance in their perceptions. For example, we found that an elderly man with progressive and unstable heart failure described feelings of lack of control and helplessness that were confirmed by his wife, who added that she felt like she was in prison with him. The general practitioner was experiencing similar disempowerment because he felt that he could do very little for such people.² In our study of the end of life care needs of South Asian patients in Scotland a participant recounted how he had suffered from discrimination and generally poor care. A linked professional confirmed that this patient's dietary needs had been unmet and his treatment been discriminatory.³

However, multiperspective data can also show differing concerns among participants. In our allergy studies, adolescents and parents gave contrasting views of the readiness of adolescents to accept responsibility for managing their condition, with parents far more anxious than adolescents about the dangers of the adolescents' ability to manage risk.⁵ In a study of mothers with early breast cancer and their children, although the mothers assumed the children were unconcerned by the diagnosis, the children described themselves as being overwhelmed.¹⁷ We found some health professionals diagnosing clinical depression at the end of

Details of multiperspective interview studies

Aims of study	Patients	Informal carers	Professional carers
To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non-malignant disease ¹	20 patients with inoperable lung cancer and 20 with advanced heart failure	Spouses, daughters, cousins, warden of sheltered accommodation	General practitioners, district nurses, community palliative care nurse, cardiologist, hospital chaplain
To inform future service developments for people with advanced heart failure ²	30 patients with advanced heart failure	Spouses, daughters	General practitioners, heart failure nurses, geriatricians, day care staff, community nurses, hospice staff, voluntary workers
To understand the experience of being diagnosed and living with a brain tumour (2005-9)	26 patients with suspected malignant glioma	Spouses, parents, daughters, sisters	General practitioners, clinical oncologists, neurosurgeons, hospital nurses, palliative care nurses, district nurses, allied health professionals, social worker, hospital chaplains
To identify the needs and service use of patients with chronic obstructive pulmonary disease, and to map a framework for an intervention study (2006-9)	20 patients with severe disease	Spouses, daughters	General practitioners, respiratory physicians, community based and hospital based respiratory nurses, nurse from day hospice
To understand end of life care needs of South Asian patients in Scotland and to understand barriers and facilitators to accessing services ³	25 South Asian patients	Spouses, children	General practitioners, specialist nurses, social worker, oncologist, occupational therapist, hospital manager
To describe the spiritual needs of patients approaching death and to explain how and by whom such needs could best be met ⁴	20 patients with advanced malignant and non-malignant disease	Spouses, children, sisters	General practitioners, hospice staff
To explore the psychosocial impact of living with anaphylaxis on adolescents and their parents; their management of the condition; and perceptions of health care provision ⁵	7 adolescents with anaphylaxis	Parents	None
To explore perceptions about anaphylaxis and its management and to formulate interventions and evaluate their acceptability to adolescents, parents, and professionals (2008-9)	26 adolescents with anaphylaxis	Parents	Allergy specialists, general practitioners, specialist nurses, school nurses, psychologists, resuscitation officers, dietitians, food and drug industry representatives, voluntary sector staff

life, when the patient considered the problems to be more existential or spiritual.⁴

Understanding of individual needs of participants

Interviews with multiple people can show different facets of the needs and coping strategies of participants in their role as patient, carer, or professional. Several general practitioners, as well as describing their need for better access to community nursing and social services to support dying patients at home, acknowledged that personal stresses and a lack of adequate training in communication were important barriers to effective care.¹

Suggestions for improving services

Linked interviews not only show the complexity of individual situations and help researchers understand deficiencies in care from different perspectives, they may also contribute to formulating relevant and workable recommendations for improving services. We organised focus groups of key professionals, patients, and carers to discuss our multiperspective interview data and used the discussion to direct formulation of a framework for planning care for people with advanced heart failure.^{2,18} Interviews with bereaved carers, for example, provided in-depth accounts of their experiences that could be integrated and compared with those of the professional carers. We have also developed service recommendations by feeding back interview findings to separate groups of professional, patient, and family participants and asking them to comment on potential interventions.

Potential pitfalls and how to avoid them

Recruitment issues

Recruiting carers into a study at around the same time as the patient might seem to add complexity. Although some patients may be less willing to participate if their family carer is also to be interviewed, it can aid recruitment of vulnerable and potentially hard to access patients because the carer moves from being a protective gatekeeper to a participant.¹⁸ Inclusion of patients who may not have an obvious family carer or friend is important, and careful exploration may identify another supportive relationship—for example, a lung cancer patient identified a sheltered housing warden.¹ We have occasionally had difficulty in recruiting busy professionals identified by patients as a key informant, and competing pressures, such as work or caring for a young family can hinder participation by family carers. Flexibility about the place and time of the interview makes refusal unusual.

Patients and carers opting to be interviewed together

Interviewing participants together is appropriate if this has been requested by participants. This can, however, have costs as well as benefits. Hearing the individual voices of the patient and carer adequately and managing information that may be sensitive or personal in the context of a joint interview can be challenging. As most interviews take place in the patient's home, a carer wishing to add information sometimes takes the opportunity for a word alone when showing the interviewer out or, for example, by inviting the researcher to look at the garden. Patients might suggest the carer make a cup of tea, which then allows them to share information they did not want the carer to hear.

When interviews are separate some carers use the patient interview as an opportunity to go out or carry out short social activities. In our brain tumour study we found that some participants chose separate interviews when they had specific issues to discuss or were not coping or communicating well with their carers.

Joint interviews are particularly valuable when patients have cognitive impairment or communication difficulties.¹⁹ Steinhäuser has sought to overcome the difficulties of joint interviewing by providing two researchers to interview the patient and carer independently, but care must be taken not to impose separate, time consuming interviews on participants.²⁰

Ethical issues

The ethical pitfalls of multiperspective research should be considered at all stages of the study. When interviewing a family or professional carer after the patient, it is often helpful to build on information from the patient interview. However, care must be taken to preserve confidentiality, particularly as carers may be curious or concerned about what has been said. Ethical issues around acting on the basis of research findings may be more acute when areas of concern—for example, about quality of care or relationships—involve or are corroborated by different interviewees. This method places emotional demands on researchers, especially if generating accounts over time, so support and debriefing from senior staff must be available.

Lack of clarity about aims and analytical strategy

Clear aims and analytical methods need to be set out and agreed at the outset because the quantity of data generated can otherwise rapidly prove overwhelming. When conducting a mixture of paired and individual interviews, both separate and joint interviews should be analysed transparently in the context in which they were generated.²¹

Conclusions

To develop personalised whole person care, we need to use patient centred research methods that can capture the multidimensional nature of the illness experience and place this understanding within a familial and health service context. Concerns about the time consuming nature of the data generation and the fact that fewer participants can be sampled have limited the use of this research method. Many of the potential barriers can be overcome with appropriate planning and groundwork. Generating data from different sources can make a major contribution to identifying people's needs and preferences.²² Such studies elicit users' views about care in the context of their experiences and integrate these with those of professionals to provide practical recommendations about how services might be delivered more effectively.

We thank the Chief Scientist's Office of the Scottish Government, the Department of Health, London, Macmillan Cancer Support, the Economic and Social Research Council, and E Wiseman for funding the studies, and Hilary Pinnock and Michael Gallagher for permitting their studies to be highlighted.

Contributors: SAM, MK, and AS conceived the paper. All the authors wrote it and have approved the final draft. MK is the guarantor.

Competing interests: None declared.

Provenance and peer review: Not commissioned; externally peer reviewed.

- 1 Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002;325:929-32.
- 2 Murray SA, Worth A, Boyd K, Kendall M, Hockley J, Pratt R, et al. *Patients', carers' and professionals' experiences of diagnosis, treatment and end-of-life care in heart failure: a prospective, qualitative interview study*. London: Department of Health, British Heart Foundation, 2007.
- 3 Worth A, Irshad T, Bhopal R, Brown D, Lawton J, Grant E, et al. Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *BMJ* 2009;338:b183.
- 4 Grant E, Murray SA, Kendall M, Boyd K, Tilley S, Ryan D. Spiritual issues and needs: perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study. *Palliat Support Care* 2004;2:371-8.
- 5 Akeson N, Worth A, Sheikh A. The psychosocial impact of anaphylaxis on young people and their parents. *Clin Exp Allergy* 2007;37:1213-20.
- 6 Murray S, Kendall M, Carduff E, Worth A, Harris F, Lloyd A, et al. Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ* 2009;339:b3702.
- 7 Woodgate RL, Degner LF. Cancer symptom transition periods of children and families. *J Adv Nurs* 2004;46:358-68.
- 8 Lewis FM, Deal LW. Balancing our lives: a study of the married couple's experience with breast cancer recurrence. *Oncol Nurs Forum* 1995;22:943-53.
- 9 Harden JK, Northouse LL, Mood DW. Qualitative analysis of couples' experience with prostate cancer by age cohort. *Cancer Nursing* 2006;29:367-77.
- 10 Back AL, Starks H, Hsu C, Gordon JR, Bharucha A, Pearlman RA. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Arch Intern Med* 2002;162:1257-6.
- 11 Schumacher KL, Beidler SM, Beeber AS, Gambino P. A transactional model of cancer family caregiving skill. *Adv Nurs Sci* 2006;29:271-86.
- 12 Dixon-Woods M, Cavers D, Jackson CJ, Young B, Forster J, Heney D, et al. Tissue samples as "gifts" for research: a qualitative study of families and professionals. *Med Law Int* 2008;9:131-50.
- 13 Kirk P, Kirk I, Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ* 2004;328:1343-6.
- 14 Clayton JM, Butow PN, Tattersall MH. When and how to initiate discussion about prognosis and end-of-life issues with terminally ill patients. *J Pain Symptom Manage* 2005;30:132-4.
- 15 Yin R. *Case study research: design and methods*. London: Sage, 2009.
- 16 Murray S, Kendall M, Boyd K, Worth A, Benton TF. Patient and carer perspectives: a man with inoperable lung cancer. *Prog Palliat Care* 2003;11:321-6.
- 17 Forrest G, Plumb C, Zieband S, Stein A. Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: qualitative study. *BMJ* 2006;332:998-1003.
- 18 Jaarsma T, Beattie JM, Ryder M, Rutten FH, McDonagh T, Mohacs P, et al. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Failure* 2009;11:433-43.
- 19 Pratt R. Nobody's ever asked how I felt. In: Wilkinson H, ed. *The perspectives of people with dementia: research methods and motivations*. London: Jessica Kingsley, 2002.
- 20 Steinhäuser KE, Clipp EC, Hays JC, Olsen M, Arnold R, Christakis NA, et al. Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliat Med* 2006;20:745-54.
- 21 Gysels M, Shipman C, Higginson IJ. Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Med Ethics* 2008;9:7.
- 22 Johnson M, Lehman R, Twycross R. *Heart failure and palliative care: a team approach*. London: Blackwell, 2006.

Research methods and reporting

Research methods and reporting is for “how to” articles—those that discuss the nuts and bolts of doing and writing up research, are actionable and readable, and will warrant appraisal by the *BMJ*'s research team and statisticians. These articles should be aimed at a general medical audience that includes doctors of all disciplines and other health professionals working in and outside the UK. You should not assume that readers will know about organisations or practices that are specific to a single discipline.

We welcome articles on all kinds of medical and health services research methods that will be relevant and useful to *BMJ* readers, whether that research is quantitative or qualitative, clinical or not. This includes articles that propose and explain practical and theoretical developments in research methodology and for those on improving the clarity and transparency of reports about research studies, protocols, and results.

This section is for the “how?” of research, while the “what, why, when, and who cares?” will usually belong elsewhere. Studies evaluating ways to conduct and report research should go to the *BMJ*'s Research section; articles debating research concepts, frameworks, and translation into practice and policy should go to Analysis, Editorials, or Features; and those expressing personal opinions should go to Personal View.

Articles for Research methods and reporting should include:

- Up to 2000 words set out under informative subheadings. For some submissions, this might be published in full on bmj.com with a shorter version in the print *BMJ*
- A separate introduction (“standfirst”) of 100-150 words

spelling out what the article is about and emphasising its importance

- Explicit evidence to support key statements and a brief explanation of the strength of the evidence (published trials, systematic reviews, observational studies, expert opinion, etc)
- No more than 20 references, in Vancouver style, presenting the evidence on which the key statements in the paper are made
- Up to three tables, boxes, or illustrations (clinical photographs, imaging, line drawings, figures—we welcome colour) to enhance the text and add to or substantiate key points made in the body of the article
- A summary box with up to four short single sentences, in the form of bullet points, highlighting the article's main points
- A box of linked information such as websites for those who want to pursue the subject in more depth (this is optional)
- Web extras: we may be able to publish on bmj.com some additional boxes, figures, references (in a separate reference list numbered w1, w2, w3, etc, and marked as such in the main text of the article)
- Suggestions for linked podcasts or video clips, as appropriate
- A statement of sources and selection criteria. As well as the standard statements of funding, competing interests, and contributorship, please provide at the end of the paper a 100-150 word paragraph (excluded from the word count) explaining the paper's provenance. This should include the relevant experience or expertise of the author(s) and the sources of information used to prepare the paper. It should also give details of each author's role in producing the article and name one as guarantor.

RESEARCH METHODS & REPORTING

Use of serial qualitative interviews to understand patients' evolving experiences and needs

Scott A Murray, Marilyn Kendall, Emma Carduff, Allison Worth, Fiona M Harris, Anna Lloyd, Debbie Cavers, Liz Grant, Aziz Sheikh

Interviewing patients over the course of their illness can give a much better picture of their experience than single interviews, but the approach is rarely used. **Scott Murray and colleagues** explain how to get the most from it

Primary Palliative Care Research Group, Centre for Population Health Sciences: General Practice Section, University of Edinburgh, Edinburgh EH8 9DX

Correspondence to: S A Murray scott.murray@ed.ac.uk

Accepted: 26 March 2009

Cite this as: *BMJ* 2009;339:b3702
doi: 10.1136/bmj.b3702

Longitudinal qualitative research offers considerable advantages over the more typical single “snapshot” techniques in understanding patients' changing experience of illness. Serial qualitative interviews are a convenient and efficient approach to developing an ongoing relationship between the participant and researcher, thereby facilitating discussion of sensitive and personal issues while also allowing exploration of changing needs and experiences.

Serial interview studies are widely used by social science researchers in anthropology, criminology, education, psychology, and social policy.¹⁻⁶ However, they remain underused in medicine.⁷ Using our experience with the technique, we suggest when researchers might wish to use serial interviews and discuss the methods, the data generated, and how to avoid potential pitfalls.

When to use serial interviews

Serial interviews are suitable for research that aims to explore evolving and complex processes or when time is needed to develop a relationship between researcher and participants. We have used the approach to study the changing experiences and needs of people with lung and brain cancers, heart failure, severe chronic obstructive pulmonary disease, and spiritual distress, and access to care for south Asian patients at end of life (table, see bmj.com).⁸⁻¹¹ Others have shown the value of this approach in, for example, understanding childhood asthma, exploring stigma related to HIV infection, reconstruction of self identity after diagnosis of chronic fatigue syndrome, complex clinician-patient interactions around requests for physician assisted suicide, and the symptom course in childhood cancer.¹²⁻¹⁶

Serial interviews can also be used to identify changes in what patients want, the most acceptable way to carry

out interventions, and which outcomes are most important to patients at what times. Allowing the participant-researcher relationship to develop over time enables the generation of more private accounts and descriptions of sensitive topics that are less accessible in initial interviews. Serial interview studies can also be embedded within complex intervention studies in order to try to elucidate causal pathways. For example, we are including serial interviews in our trial of using lay outreach workers for smoking cessation in order to understand why they are (or are not) effective.

How do you conduct serial interview studies?

Recruitment

The timing of initial recruitment is important and is best driven by a sound understanding of the likely trajectory of the illness and the main issues to be explored.¹⁷ For example, we recruited patients with lung cancer at the point of diagnosis; those with heart failure at the time of their admission to hospital—when supportive and palliative care needs become particularly relevant; and patients with glioma before formal diagnosis in order to capture their experiences from this distressing time onwards. However, when prognostic uncertainty is great, the timing of recruitment for initial and subsequent interviews can be difficult to determine.

Location of recruitment also needs consideration. Identification in hospital can be successful for patients with rare conditions, who can then be followed up in the community. However, different situations may require recruitment in other healthcare settings or even outside health care. Irrespective of where participants are recruited from, working closely with all professionals involved is crucial to ensure appropriate and ongoing access to participants. In order to make the best use of resources inclusion and exclusion criteria must be well defined, including the stage of the illness.

Data generation

Variable attrition rates and illness progression will affect the timing of second and subsequent interviews. For example, we used three month intervals in people with recently diagnosed lung cancer but six monthly inter-

SUMMARY POINTS

Serial interviewing studies can give important insights into patients' changing experiences of illness

The increased contact with participants allows a deeper relationship to develop, facilitating discussion of sensitive issues

Theoretical and methodological concerns can be overcome with careful planning

Although the method is time consuming, the benefits are well worth achieving

views in people with chronic obstructive pulmonary disease, which progresses less rapidly. Researchers should identify expected transitions or key points in the course of an illness and return to speak with participants at those stages. We have also found it useful to use telephone contact to assess if an interview should be brought forward to capture a changing event. The time needed for repeat interviews must be factored into the research design timetable.

Data generation must continue long enough to describe and understand the trajectory being studied. In patients with lung cancer, for example, data collection for 12 months from diagnosis will capture most deaths, but longer will be needed in a study of frail elderly patients.

Analysis

Initial analysis of transcripts of individual interviews and field notes should take place immediately, alongside continuing data generation. This allows emerging themes and concepts to be further tested and developed in subsequent interviews. Analysis may also be done across all first, second, and subsequent interviews or data synthesised from interviews at specific key points, such as immediately preceding death.

Adequate time and resources need to be allocated to allow the various longitudinal analytical opportunities to be fully exploited. Analysing all transcripts for each person as a longitudinal single unit will provide a sense of individual experience, whereas broad thematic approaches build cross-cutting themes, but at the expense of individual contexts. The longitudinal datasets generated, being typically rich in narratives, allow innovative approaches to both transcribing and analysis. For instance, as the required coding in qualitative analysis can result in fragmentation and decontextualisation, we have transcribed some parts of the interviews of heart failure and lung cancer patients in stanza forms, as epic poetry. These can provide an accessible insight into the patient's experience.

What type of findings might you expect?

Issues that change over time

Serial interviews can elicit changing needs or opinions—for example, in our lung cancer study some participants went from initial enthusiasm about having chemotherapy to regret, and others from refusal to deep appreciation of hospice care in later interviews. We were also able to capture the fluctuating existential anguish of increasing physical and cognitive debility in serial interviews with glioma patients and their carers. Similarly, Baker and colleagues interviewed bone marrow transplant recipients and noted changing physical problems and anxiety levels as the treatment progressed, with a feeling of impending doom emerging in later interviews.¹⁸ The serial interviews provided a rich insight into the multifaceted roles of patients within their families and communities and the way in which these served to preserve patients' identity over time.

Serial interviews can also show how patients' experiences can be affected by external factors such as the

influence of health services on their conceptualisation of illness over time.^{19,20} Furthermore, serial interviews allow fluctuating and often asynchronous patterns of physical, social, psychological, and spiritual distress to be discerned. The approach allowed us to map typical trajectories of physical decline in people with cancer and organ failure.²¹ We were also able to identify typical but asynchronous trajectories of psychological, social, and spiritual distress as disease progressed in patients with advanced lung cancer.^{21,22} We were able to describe archetypal typologies of decline by following individual cases over time. This gave a much clearer picture than would have been possible by simply comparing snapshot data at different stages in the disease.

Rich and contextualised accounts

Repeating interviews allows narratives to unfold, revealing the complexity of individual situations, and helps participants and researchers to highlight deficiencies of care and make suggestions to improve services. Experiences since the last interview can be shared, with the earlier findings being developed and reflected on in the context of an evolving, participant-researcher relationship. The resulting continuous and changing account would be difficult, if not impossible, to construct from a series of snapshot interviews. Additionally, the trust fostered by repeated contact enables participants to voice sensitive or embarrassing issues and allows more private (as opposed to public) accounts to emerge.²³ We have found that repeated interviews give participants implicit permission to broach what was previously unspeakable, facilitating frank and honest discussions that might otherwise not have occurred. Detailed and contextualised accounts of sensitive illness experiences can therefore emerge.

Pitfalls and how to avoid them

Ethical issues

Ethical problems are potentially heightened in longitudinal research, including concerns around serial consent, especially if the patient is deteriorating or vulnerable.^{19,24} Intrusion, dependency, and distortion of life experience must also be avoided.²⁵ But we have found that patients can, and indeed want to, talk about personal and sensitive issues such as death, dying, and bereavement. Patients have said that it is sometimes easier for them to talk to a researcher rather than a clinician about these issues, and that by voicing their internal fears they have been more able afterwards to speak to their family members and friends. Serial interviews also give participants the opportunity to voice their concerns and distress and make a societal contribution through research in response to the care they have received.^{26,27}

Serial interview research can place considerable demands on researchers because it is inherently an emotionally charged process. Researchers' responsibility does not end with a final interview, and it is important to protect the wellbeing of researchers as well as participants. Accordingly, we recommend counselling and debriefing sessions for both researchers and transcribers, who should ideally have adequate maturity, experience, and access to personal or emotional support.²⁴ Our experi-

ences confirm that these concerns about wellbeing can be adequately addressed and that interviewing very ill patients need not be exceptionally stressful.²⁸

Attrition

As with any longitudinal research, attrition can be problematic. For example, in one study of people with glioma, none of the planned second interviews were possible because of participants' cognitive decline and lack of energy after radiotherapy.²⁹ Steinhauser and colleagues emphasise the importance of establishing participant-interviewer rapport from the first point of contact to try maximise retention.³⁰ If a firm relationship is built up between researcher and participant, few participants will be lost, except through debility or death. Nonetheless, attrition should be factored into the design of the study. We found that by recruiting and interviewing patients and their relatives early in their illness we were able to establish relationships that facilitated interviews with relatives after patients' deaths. Grieving relatives often felt more able to take part in a bereavement interview with someone they knew and trusted, and who knew and understood their journey.

Data overload

The serial interview approach inevitably generates a large volume of interviews. The data can become difficult to manage, particularly when second and subsequent interviews have started. Effective planning is therefore essential from the outset. Furthermore, the time consuming nature of the analysis creates the danger that the process is becoming unmanageable—something that has been described as an analytical albatross.³¹

Conclusions

An understanding of the dynamic effects of disease on people's everyday lives is a prerequisite to delivering more accessible and acceptable care. People centred longitudinal research methods can make a major contribution in our understanding.³² Serial in-depth interviews are a powerful method that resonates with the clinical aim to provide continuity of contact with patients and their families. The method is also possibly the most affordable in-depth data generation technique, and our experiences suggest that it is also likely to prove acceptable to clinicians.

Lack of awareness and concerns about some theoretical, methodological, and planning considerations currently limit use of this study design. Many of these barriers can be overcome with appropriate planning and groundwork, and although the approach is research intensive, we believe the benefits are well worth achieving. Participants consistently report serial interviews as helpful rather than harmful; researchers also find that such interviewing can be rewarding.²⁴

We thank the Chief Scientist's Office of the Scottish Government, the Department of Health, London, Macmillan Cancer Support, the Economic and Social Research Council, and E Wiseman for funding the studies.

Contributors: SAM, MK, and AS conceived the paper, and all the authors wrote it and have approved the final draft. SAM is the guarantor.

Competing interests: None declared.

Provenance and peer review: Not commissioned; externally peer reviewed.

- Kemper R, Royce A. *Chronicling cultures: Long term field research in anthropology*. Walnut Creek, CA: AltaMira, 2002.
- Smith D, McVie S. Theory and method in the Edinburgh Study of Youth Transitions and Crime. *Br J Criminology* 2003;43:169-95.
- White RT, Arzi HJ. Longitudinal studies: designs, validity, practicality, and value. *Res Sci Educ* 2005;35:137-49.
- Gilligan C. *In a different voice: psychological theory and women's development*. London: Harvard University Press, 1993.
- Corden A, Millar J. Time and change: a review of qualitative longitudinal research literature for social policy. *Soc Pol Society* 2007;6:583-92.
- Smith N, Lister R, Middleton S. Longitudinal qualitative research. In: Becker S, Bryman A, eds. *Understanding research for social policy and practice: themes, methods and approaches*. Bristol: Policy Press, 2004.
- Lewington S, Whitlock G, Clarke R, Sherliker P, Emberson J, Halsey J, et al. Blood cholesterol and vascular mortality by age, sex, and blood pressure: a meta-analysis of individual data from 61 prospective studies with 55,000 vascular deaths. *Lancet* 2007;370:1829-39.
- Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002;327:929.
- Murray SA, Worth A, Boyd K, Kendall M, Hockley J, Pratt R, et al. *Patients', carers' and professionals' experiences of diagnosis, treatment and end-of-life care in heart failure: a prospective, qualitative interview study*. London: Department of Health, British Heart Foundation, 2007.
- Worth A, Irshad T, Bhopal R, Brown D, Lawton J, Grant E, et al. Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *BMJ* 2009;338:b183.
- Grant E, Murray SA, Kendall M, Boyd K, Tilley S, Ryan D. Spiritual issues and needs: perspectives from patients with advanced cancer and non-malignant disease. A qualitative study. *Palliat Support Care* 2004;2:371-8.
- Peterson JW, Sterling YM. Children's perceptions of asthma: African American children use metaphors to make sense of asthma. *J Pediatr Health Care* 2009;23:93-100.
- Buseh AG, Stevens PE. Constrained but not determined by stigma: resistance by African American women living with HIV. *Women Health* 2006;44:1-18.
- Whitehead L. Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: a longitudinal qualitative study. *Int J Nurs Stud* 2006;43:1023-31.
- Back AL, Starks H, Hsu C, Gordon JR, Bharucha A, Pearlman RA. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Arch Intern Med* 2002;162:1257-65.
- Woodgate RL, Degner LF. Cancer symptom transition periods of children and families. *J Adv Nurs* 2004;46:358-68.
- Lawton J, Peel E, Parry O, Douglas M. Shifting accountability: a longitudinal qualitative study of diabetes causation accounts. *Soc Sci Med* 2008;67:47-56.
- Baker F, Zabora J, Pollard A, Wingard J. Reintegration after bone marrow transplantation. *Cancer Practice* 1999;7:190-7.
- Lawton J. Gaining and maintaining consent: ethical concerns raised in a study of dying patients. *Qual Health Res* 2001;11:693-705.
- Lawton J, Peel E, Parry O, Araoz G, Douglas M. Lay perceptions of type 2 diabetes in Scotland: bringing health services back in. *Soc Sci Med* 2005;60:1423-35.
- Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;330:1007-11.
- Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. *J Pain Symptom Manage* 2007;34:393-402.
- Cornwell J. *Hard-earned lives: accounts of health and illness from east London*. London: Tavistock, 1984.
- Kendall M, Harris F, Boyd K, Sheikh A, Murray SA, Brown D, et al. Key challenges and ways forward in researching the "good death": qualitative in-depth interview and focus group study. *BMJ* 2007;334:521-4.
- Yates P, Stetz KM. Families' awareness of and response to dying. *Oncol Nurs Forum* 1999;26:113-20.
- Lowes L, Paul G. Participants' experiences of being interviewed about an emotive topic. *J Adv Nurs* 2006;55:587-95.
- Harris FM, Kendall M, Bentley A, Maguire R, Worth A, Murray S, et al. Researching experiences of terminal cancer: a systematic review of methodological issues and approaches. *Eur J Cancer Care* 2008;17:377-86.
- Murray SA, Sheikh A. Serial interviews for patients with progressive diseases. *Lancet* 2006;368:901-2.
- Wildeheim AK, Edvardsson T, Pahlson A, Ahlstrom G. A family's perspective on living with a highly malignant brain tumor. *Cancer Nurs* 2002;25:236-44.
- Steinhauser KE, Clipp EC, Hays JC, Olsen M, Arnold R, Christakis NA, et al. Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliat Med* 2006;20:745-54.
- Holland J, Thomson R, Henderson S. *Qualitative longitudinal research: a discussion paper*. Economic and Social Research Council, 2006. www.lsbu.ac.uk/families/workingpapers/familieswp21.pdf.
- Riley J, Ross JR. Research into care at the end of life. *Lancet* 2005;365:735-7.